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THERAPEUTIC NURSING PRACTICE IN STROKE REHABILITATION

**The Development and Evaluation of a Therapeutic Nursing Intervention
in Stroke Rehabilitation**

Christopher Richard Burton

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Department of Health Sciences

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Abstract

This thesis provides a strategy for the advancement of nursing practice in stroke rehabilitation. Specifically it develops and evaluates a therapeutic nursing intervention, focusing on the use of educative and supportive interventions to promote coping, and adaptation to the consequences of disease in patients. Traditional approaches to the organisation and delivery of stroke services are shown to be limited in their ability to address themes raised in stroke patients' experience. To address these themes, a framework for therapeutic nursing practice has been proposed which is then explored in a systematic review.

The framework for therapeutic nursing practice in stroke rehabilitation was implemented through an existing stroke nurse role. In practice stroke patients were provided with intensive post-discharge support by the stroke nurse. In this way, educative and supportive interventions were provided consistently across the hospital and into primary care. The effectiveness of this role development was compared with usual clinical practice, as defined by national norms.

Effectiveness was determined in a pragmatic randomised controlled trial developed using the Medical Research Council (2000) guidance for the development and evaluation of complex interventions. The trial was augmented by three associated studies focusing on the acceptability of the trial intervention for patients and carers, a detailed study of the specific activities undertaken as part of the study intervention, and an exploration of the associated professional and managerial issues. These qualitative elements of the trial indicate that the provision of an overarching, therapeutic nursing intervention was acceptable to

patients and carers, although they continued to face significant challenges from their stroke. The implementation of this type of nursing intervention challenges existing boundaries of health care provision, and therefore requires considerable managerial and professional support.

The trial indicated that this complex intervention is promising, and warrants closer attention. Patient perceptions of general health, assessed using the Nottingham Health Profile, were enhanced by the intervention, particularly in the areas of social isolation and emotional distress. This improvement was most noticeable between three and twelve months, where the mean improvement in the control group was 8.81 (-16.75, 34.36) units and 44.37 (19.63, 69.10) units in the experimental group. The intervention may also have a protective effect in terms of physical dependence after three months, and carer strain up to three months. No significant effects of the intervention were noted for depression or activities of living. The intervention requires further study in other settings, with particular emphasis on the identification of those features of the intervention that are most effective.

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Perhaps most importantly I would like to thank my partner John, and my parents whose understanding and unwavering support over the years has enabled me to complete this work. This thesis is dedicated to them.

Declaration

I declare that this thesis is the result of my own work. The material contained in the thesis has not been presented, nor is currently being presented, either wholly or in part for any degree or qualification.

Signed.....

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Preface

There is little agreement across professional groups on what constitutes a therapeutic nursing intervention in stroke rehabilitation. If rehabilitation is to be a multidisciplinary enterprise however, it is essential that the contribution of all professional groups is understood and valued. The lack of a substantial research base has hindered the ability of nursing to delineate and promote its therapeutic input to the rehabilitation effort.

This thesis presents a study that constructs and tests a new, therapeutic nursing intervention for people affected by stroke. The intervention is complex in nature, and is located within a framework of therapeutic nursing in stroke rehabilitation. It acknowledges the importance of including a long-term vision in planning and delivering stroke services, and is aimed at easing the immense difficulties faced by those with stroke after discharge from in-patient care. Its development is described in Part One of the thesis.

The thesis will construct a theoretical framework of the constitution of therapeutic nursing in stroke care from key literature. The framework will address the mismatch between professional and patient perspectives of stroke, and will stress the importance of educative, supportive and other interventions which help people affected by stroke come to terms with the consequences of disease. A systematic review of scientific literature will be undertaken to explore the congruence between the emerging theoretical account and the research base. The first part of this thesis will conclude with the implementation of the framework in clinical practice. The framework is operationalised in a focus on educative and

supportive interventions within a nursing case management approach, delivered by a practitioner operating at an advanced level of practice.

Therapeutic practice in nursing will be shown to incorporate a diverse and complex package of inter-related strategies and interventions. As such even the delineation of goals for this mode of practice to lead evaluation activity is problematic. New strategies for evaluation research have however offered a blueprint for the development of programmatic approaches to research in this area (Medical Research Council, 2000). Part Two of the thesis will build on existing strategies for the evaluation of complex interventions in health care. These will be used to explore the clinical effectiveness of providing therapeutic nursing interventions through continuing nursing case management in stroke rehabilitation. Recommendations for clinical practice and future research will be presented, based on the entire thesis.

The work for this thesis was completed during a six year period when I was employed as a full-time lecturer in nursing. In many respects the thesis maps my professional and academic development throughout that period, as I was able to assimilate learning from the health sciences modules at the University of York, and experience of undertaking research in the clinical field. Chapters Two to Four are based on preliminary published work which underpinned the development of research ideas and proposals submitted for research funding. As such these chapters are structured in a more traditional format than Chapter Five. This chapter, the systematic review, was completed after this preliminary work, and represents a significant shift in both thinking and method. The second part of the thesis demonstrates clear links between the taught component of research training

in the Department of Health Sciences. The award of funding from the Regional NHS Research and Development Directorate was critical to supporting the successful completion of the trial. The grant enabled me to reduce some of my teaching and other academic commitments, and to focus on recruitment and data collection.

PART ONE

Chapter 1

Introduction

Stroke: the disease.

From a bio-medical perspective, stroke is defined as a focal neurological deficit due to a vascular lesion. This lesion is usually caused by an embolism from a distant site with resulting infarction of brain tissue. This mechanism accounts for nearly 70% of all strokes. Other causes include thrombosis of a cerebral vessel with resulting infarction, haemorrhage into the brain, or subarachnoid haemorrhage (Richards and Baker, 1988; Kumar and Clark, 1990). The clinical picture is variable, and depends on the site and extent of the infarct. It is usually of rapid onset, and, by definition symptoms last longer than 24 hours if the patient survives (World Health Organisation, 1971). This is the distinguishing feature between a stroke and a 'mini-stroke' or transient ischaemic attack (TIA), where signs and symptoms resolve within 24 hours.

Hemiplegia, as the commonest symptom of stroke, is caused by infarction of the internal capsule following thromboembolism of the middle cerebral artery. Associated signs are those of an upper motor neurone lesion of one side. Aphasia is common, particularly when the dominant brain hemisphere is affected. The limbs are at first flaccid, headache is unusual and consciousness is generally not lost. Reflexes may recover over time and may become exaggerated. Weakness is maximal at first, and may recover slowly over the course of days, weeks or months (Kumar and Clark, 1990).

Stroke: epidemiology.

Stroke is responsible for nearly 13% of all deaths in the developed world, accounting for almost 12% of all deaths in England and Wales in 1990 (Department of Health, 1992). It affects mainly the elderly, with 50% of strokes occurring in people aged 55 and over. The incidence of all strokes (other than subarachnoid haemorrhage) increase rapidly with age, with rates for males higher than females in most age groups (McNeil, King, Jennings *et al*, 1990). The disease is uncommon below the age of 40, with subarachnoid haemorrhage accounting for 50% of all strokes for ages up to 30 years.

Gender and age appear to play a significant role in determining the incidence of stroke. Women tend to be slightly older than men at the time of first stroke (Wyller, 1999). This may explain sex differences in case fatality rates, where a higher proportion of women to men who have a stroke die as a result. There appears to be little relationship between gender and the stroke subtype other than a slightly higher proportion of stroke due to haemorrhage in men.

In 1995 the World Health Organisation established age and sex standardised incidence rates for stroke in a comprehensive review of incidence from 16 European and 2 Asian populations. Here the age standardised stroke incidence rate was higher in men across all age groups, with a male-female ratio ranging from 1.2:1 to 2.4:1. Whilst the incidence of stroke in the UK has been variable over the past few decades, these rates are consistent with estimates of between 1 and 2 strokes per 1000 population per annum in the UK and Europe (Bamford, Sandercock, Dennis *et al*, 1988).

In the United Kingdom (UK) the incidence of stroke in the black Afro-Caribbean population is nearly twice as high, although the causes of this increase have yet to be fully explained. The first population based study was undertaken only recently in the UK, and explored the relationship between stroke type, risk factors and ethnic group (Hajat, Dundas, Stewart *et al*, 2001). This study, based on a stroke register of over 1,254 patients, demonstrated differences in the presence of some risk factors for stroke, including other disease and behavioural factors, across ethnic groups.

The prevalence of stroke in the UK population is increasing, possibly due to improvements in treatment during the early stages of the disease process. The Stroke Association (1994) maintains that 350,000 people in the UK are directly affected by stroke, and that each year 100,000 people will suffer a first stroke. 70% of stroke patients survive the initial disease onset, and will require some form of rehabilitation. Stroke can have a catastrophic impact on an individual, with a wide range of far-reaching physical, psychological and social sequelae. The gender differences in prevalence reflect the differences in longevity, which is higher in women than men. Whilst fatality from stroke is higher in women than men at 80 years of age or over, the prevalence of stroke in this age group is higher in women (Geddes, Fear, Tennant *et al*, 1996).

It has been postulated that both prevalence and incidence of stroke have consistently been underestimated. There are difficulties in describing the frequency of stroke due to two factors: difficulties in detection and labelling cases on clinical grounds alone. Only a small proportion of stroke deaths come to post

mortem, and as such certified deaths are at best only a crude index of disease burden (Donaldson and Donaldson, 1983).

Stroke: associated health and social care needs.

Whilst the delineation of health and social care has been made in policy (Department of Health, 1990), the consequences of stroke demonstrate that this split is clearly problematic in practice, and that health and social care needs are heavily inter-dependent. The description of the signs and symptoms of stroke earlier in this chapter fails to capture either the complexity or the inter-dependency of these effects and needs.

An extensive survey of stroke patients and their families (n=1376) undertaken by an advocacy group, the Stroke Association, demonstrates to some degree the breadth of problems faced by people after stroke (Stroke Association, 1994). In this sample, nearly two-thirds of all those who had experienced a stroke had problems with mobility, their ability to communicate verbally or on paper, or their short term memory. Nearly all those 50 years or under had been forced to give up work after stroke. Nearly a half of those questioned had experienced a drop in household income, although this figure was considerably higher when adjusted for age. The provision of support services in the community was demonstrated to be patchy, often failing to reflect the needs and priorities of patients. Whilst this survey may have been influenced by the strategic agenda of the commissioning organisation, its conclusions are consistent with the majority of work in this area.

A key consequence of stroke is depression, which affects a sizeable proportion of those people affected by stroke (Nouri, Flannaghan, Sutcliffe *et al*, 1997). In a study of 976 stroke patients, the proportion of patients with depression at three weeks, six months and twelve months was shown to be nearly two-thirds (Wade, Legh-Smith and Hower, 1987). Here, depression was assessed using an established tool, the Wakefield Depression Scale (Snaith, Ahmed, Mehta *et al*, 1971). The incidence of depression however could not be explained simply as a consequence of the physical or social aftermath of stroke alone. An appraisal of other related studies has shown that whilst the general frequency of depression was similar, inconsistencies in the relationship of depression with activities of daily living and social isolation were evident.

The relationship between the clinical consequences of stroke, and the wider experiences of those living with those consequences, has also shown to be inconsistent. For example, the relationship between physical disability and individual handicap has been shown to be variable and essentially weak, with little predictive ability (Sturm, Dewey, Donnan *et al*, 2002).

Stroke: current health policy.

The demand placed on UK health care resources by stroke has precipitated its priority status as a health issue. 10% of medical beds within the National Health Service are taken by people with stroke, consuming nearly 4% of the total NHS budget (Office of Health Economics, 1988). It is perhaps unsurprising therefore that stroke has consistently been accorded priority status for health prevention since the publication of the health strategy 'Health of the Nation' in 1992, and

more recently 'Our Healthier Nation' in 1997 (Department of Health, 1992; 1997a). Demographic changes over the next twenty years suggest that the demand for hospital and community resources for those affected by stroke may increase dramatically (Department of Health, 2001a).

Risk factors for stroke are well established in the literature, and include "age, systolic blood pressure, the use of anti-hypertensive therapy, diabetes mellitus, cigarette smoking, prior cardiovascular disease (coronary heart disease, cardiac failure, or intermittent claudication), atrial fibrillation, and left ventricular hypertrophy by electrocardiogram" (Wolf, D'Agostino, Belanger *et al*, 1991 p312). Whilst strictly speaking the use of anti-hypertensive therapy is a risk marker rather than factor, the paper does demonstrate the complex aetiology of stroke. The relationship between risk factors for stroke and other socioeconomic factors remains unclear (Hart, Hole and Smith, 2000; Redfern, McKevitt, Dundas *et al*, 2000). The interaction of risk factors in UK populations has been examined in an extensive study in the north west of England using a case control method (Du, McNamee and Cruickshank, 2000). The study demonstrated that a baseline odds ratio for stroke from hypertension was increased from 2.6 (1.7, 3.9) to 6.1 (2.7, 13.7) by smoking. A threefold increase in risk was associated with pre-existing cardiac disease, diabetes or obesity, and an eightfold increase with hypertension compounded by atrial fibrillation or a history of transient ischaemic attacks. The study concluded that the risk of stroke increases cumulatively with the presence of risk factors, particularly in hypertensive patients.

The publication of National Service Frameworks as strategies for the development of services in key clinical areas, has presented the opportunity to redefine

benchmarks for the quality of health care in these areas. The absence of a National Service Framework for stroke in its own right will however present a considerable challenge to those with a specialist interest in the field. Whilst the consequences of stroke have the potential to consume a relatively large proportion of health and social care spending, working in this area can be viewed as heavy and demanding (Gibbon 1991), with little of the relative glamour of a high-technology critical care environment.

Stroke is however specified as Standard Five in the National Service Framework for Older People (Department of Health, 2001a), and has four main component parts:

- prevention
- immediate care
- early and continuing rehabilitation, and
- long-term support.

Stroke prevention focuses clearly on the most significant risk factors: the management of transient ischaemic attacks, carotid stenosis, hypertension and atrial fibrillation. Other components of the standard reflect the content of the National Clinical Guidelines for Stroke, and are described later in this chapter.

The general principles espoused in the National Service Framework are also intended to be applied to stroke care, focusing on

- the holistic needs of individual patients, and
- the promotion of an active and healthy life.

Whilst there is nothing new in the rhetoric of either of these two principles, there are some clear messages for the development of stroke services. There appears to

be an emerging emphasis on addressing the full range of consequences of stroke, and the perspectives of those that experience the disease. Whether the structure and organisation of health and social care services will facilitate or prevent these aims being met remains unclear.

Stroke: evidence-based practice.

The strategic agenda for health care over the past decade has included evidence-based practice as a central tenet (Department of Health, 1996; 1997b). National variations in treatment and care, coupled with ever increasing scrutiny of public spending have precipitated successive government policies with the aim of improving the management of the health care budget. Partly as a consequence, health care professionals have been required to demonstrate the use of best evidence in informing practice decisions.

Much of the evidence-base in stroke rehabilitation relates to the organisation of care and treatment as a multidisciplinary and co-ordinated enterprise. The evidence specific to the beneficial effects of organised stroke care has been considerably strengthened over the last ten years by the work of the Cochrane Stroke Group. Although early reviews included stroke wards and peripatetic stroke teams (Langhorne, Williams, Gilchrist *et al*, 1993), the emphasis of the intervention being studied was the stroke unit as a given geographical entity. The potential threat to review validity by the inclusion of both was however recognised in the review by the inclusion of a sensitivity analysis which reported data from trials of both types of intervention separately and cumulatively. The implementation of stroke units may be problematic, with descriptions of acute

stroke units, rehabilitation stroke units, and comprehensive stroke units in the professional literature (Stevens, 1989; O'Connor, 1996).

The current evidence-base is encapsulated in the National Clinical Guidelines for Stroke Rehabilitation, developed by a multiprofessional working group, published by the Intercollegiate Working Party for Stroke in 2000 (Intercollegiate Working Party for Stroke, 2000). The guidelines were developed from systematic reviews of computerised databases, registers of stroke research and from consensus developed within the working group. The complexity and diverse nature of the stroke rehabilitation literature apparently predisposed against the use of rigid search strategies in the development of the guidelines, and the preamble indicates that individuals leading specific topics were encouraged to use their initiative in identifying useful research. This limitation coupled, with the biomedical focus of the electronic databases referred to, would suggest that the guidelines, as with all others, require careful consideration prior to implementation and regular review.

With respect to stroke, strategic documents designed to increase the volume of cost-effectiveness research in health care (for example, Drummond, 1994) appear to have had little impact (Keith, 1996). This probably reflects the volume of research in stroke generally, which is limited, rather than the perceived value of health economics in decision-making in health care. Additionally, where research is set at a programme level of intervention, such as the effectiveness of stroke units, the development of responsive economic models is more complicated than for discrete health care interventions. For complex interventions the potential resource consequences, and in particular the potential diversion of resources from other services become increasingly numerous. Where economic indicators have

been included in stroke rehabilitation research, these have tended to be limited to proxies such as the length of stay and the type of follow-up service (Jorgensen, Nakayama, Raaschou *et al*, 1995). *Effective Health Care* has recommended therefore that research in stroke rehabilitation incorporates an economic evaluative element (University of Leeds, 1992).

Stroke: multidisciplinary perspectives.

The effects of stroke can include difficulties with physical movement, verbal and other forms of communication, and the full range of activities and behaviours that constitute daily living. It is therefore unsurprising that the stroke rehabilitation effort requires access to a wide range of professional and technical resources. The evidence-base for stroke rehabilitation would suggest that where services are co-ordinated to include a multidisciplinary perspective, then patient outcomes are enhanced (Stroke Unit Trialists' Collaboration, 2002).

The notion of multidisciplinary care in the literature is however diffuse: we know very little about how best to organise a multidisciplinary approach. Various strategies can be found in the literature, including case conferences, shared records and shared learning. Where these strategies have been subject to detailed exploratory study (Gibbon, 1999), the rhetoric and the realities of multidisciplinary practice become clear. For example, in a study of case conferences (n=111), analysis of their content indicated that their primary purpose was to disseminate information. Whilst the conferences may have assisted in the development of perceptions of team cohesiveness and multidisciplinaryity, they did

little to facilitate the meaningful sharing of ideas, knowledge, clinical experience or the involvement of patients and carers.

Considerable rhetoric surrounds the notion of multidisciplinary practice, which may after all depend solely on the personalities of the individual practitioners involved in a patient's care. True collaboration must involve the sharing of responsibility and authority for decision-making, together with the use of resources, and the sharing of knowledge between all professional groups (Gibbon, 1999). The dangers in developing multidisciplinary care are however not insignificant. Organisational inertia may be an unintentional by-product of collaboration, where a focus on consensus has the potential to lose the unique nature of the contributions of different professional groups. It may be best therefore to view multidisciplinary practice as a relative term, where the willingness to understand, value and ultimately use the different contributions to the overall service is paramount. This viewpoint stresses the importance of defining and building the research base of the different professions involved in stroke rehabilitation.

Whilst it is clear that stroke rehabilitation is a multidisciplinary enterprise, this thesis focuses on the therapeutic contribution of one professional group. If the policy of collaboration between professional groups is taken to be a worthy goal of service development, and the uniqueness of the input provided by each professional group is accepted, then the evidence-base of each professional group has to be of a comparable volume and standard. Whilst much is written in the nursing literature about the importance of research and evidence-based practice, nursing has been slow to build a useful and credible research base (Cullum, 1997).

The execution of rigorous research studies that focus on nursing issues in stroke rehabilitation is therefore extremely important. This does not imply that many of the issues raised in the thesis are irrelevant to other professional groups. The thesis will address a nursing response to those issues, by focusing on an aspect of multidisciplinary care unique to nursing: the therapeutic relationship between patient and nurse.

Stroke: rehabilitation perspectives

Rehabilitation is described variously as either an approach or stance to practice, a set of defined and discrete interventions, or an intervention in its own right. Nevertheless the focus of many definitions of rehabilitation in the recent literature is on improvement in physical functioning in the presence of disease, rather than cure (Royal College of Physicians, 1986; Evans, Connis, Hendrick *et al*, 1995; Garrison, 1995; Jelles, Van Bennekom and Lankhorst, 1995; Burton, 2000a). This focus has persisted since the inception of modern approaches to rehabilitation largely to address the consequences of injury during the second world war.

The relationship between rehabilitation and other approaches to treatment and care in the UK is again problematic, with little consensus evident in the literature. Comparisons can be made between acute simple disease models and chronic complex illness models (Pawlson, 1994), and short or long-term rehabilitation models (Robinson, 1988) which highlight alternative structures, processes and outcomes of rehabilitation. In the nursing literature, Waters (1996 p242) maintains that rehabilitation is 'the whole process of enabling and facilitating the restoration of a disabled person to regain optimal functioning (physically, socially and

psychologically) to the level that they are able or motivated to achieve'. The utility of restorative, functional approaches to rehabilitation in meeting the needs of stroke patients will be explored in this thesis.

As a satisfactory model of rehabilitation to underpin the construction of this thesis was not located, a decision was made to focus primarily on the perspectives of those receiving rehabilitation, and in particular their expectations and experiences. By comparing and contrasting this perspective with the prevalent professional approaches to rehabilitation, a theoretical framework responsive to the major stakeholders in rehabilitation could be constructed and used in later work.

Chapter 2

User Perspectives on Recovery

Introduction to the chapter

The importance of stroke as a disease that has significant capacity to affect population health has been established. Whilst it is encouraging that progress has been made in identifying effective strategies for the organisation of services for this population group, the potential consequences of the disease are complex and long-term in nature. It is essential therefore that care and treatment options for those affected by stroke fit closely with their needs and aspirations. This chapter will therefore explore user perspectives on recovery from stroke by drawing on previous research in this area, and reporting on an empirical investigation of experiences specifically undertaken to inform the development of this thesis.

Review of selected literature

Much has been written, both in policy and the professional literature about the virtues of adopting a patient focus in both the development and evaluation of health care. In fact this is a key sentiment which underpins much of the content of the National Service Framework for Older People (Department of Health, 2001a) described in the previous chapter. How to identify the perspective of patients is however complex, with strengths and weaknesses apparent in the full range of methodological options open to researchers in this area. Any approach to the identification of patient perspectives through the imposition of beliefs about what is important to patients, as in the case of a highly structured questionnaire without a strong theoretical foundation, can however be open to criticism. Other approaches, which tend to rely on smaller samples, may appear to lack the generalisability of the more traditional survey or other cross-sectional approaches

to the collection of data. In some respects this is a fallacy, as strictly speaking phenomenological and ethnographic studies in health care are inductive in that they aim to build an understanding of what issues are important to patients, rather than to predict their prevalence (Morse and Field, 1995). This chapter aims solely to highlight the concerns of people affected by stroke, and will therefore only include studies which have sought to describe experiences from their point of view. One of the studies included in this review (Burton, 2000b) has directly influenced the development of the clinical intervention at the centre of this thesis, and will therefore be studied in more detail.

It is clear that, whilst studies on the experience and acceptability of care and therapy can be found (Pound, Bury, Gompertz *et al*, 1995; MacDuff, 1998), there is generally a dearth of literature that specifically focuses on the individual's experience of the disease itself (Doolittle, 1991; McLean, Roper-Hall, Mayer *et al*, 1991).

As a disease process the bio-medical interpretation of stroke (neuronal and functional recovery) or a two-stage model (acute and rehabilitation phases) appear to predominate (Speech and Dombovy, 1995). There is a developing body of stroke rehabilitation literature that recognises the importance of including the patient's perspective in outcome measurement, by the development of sensitive outcome assessment strategies (Seale and Davies, 1987; de Haan, Aaronson, Limburg *et al*, 1993; Wyller, Sveen, Sjødring *et al*, 1997).

The most recent review of literature in this area was published in 1997 (Hafsteinsdóttir and Grypdonck, 1997), and combines the findings of four studies

(Mumma, 1986; Doolittle, 1991; Folden, 1994; Häggström, Axelsson and Norberg, 1994) and one earlier review (Doolittle, 1988). Although no account is given of the strategies used to identify suitable papers to be included in the review, the limited number is likely to be representative given the plethora of calls for more research in this area.

Whilst the study undertaken by Mumma (1986) highlights patient perceptions of loss, a later, and more extensive, ethnographic study demonstrates a recovery path for stroke (Doolittle, 1992). This study was set in the context of in-patient care and discharge, and brings to life the extent of the challenges and dilemmas that people who suffer a stroke experience. Six themes were identified in the data:

- stroke in evolution
- the meaning of hospitalisation
- living with uncertainty
- differing medical and personal views
- facing the night, and
- discharge home.

Although these themes focus attention on the experience and psychological consequences of physical disability, the findings suggest the importance of the social context in the way in which participants evaluated their own recovery.

Doolittle's (1992) study of thirteen people affected by stroke strongly suggests that patient and professional interpretations of recovery can differ significantly, and consequently the reference frames for the evaluation of recovery can be at odds with each other. Professionals appear to evaluate progress using benchmarks relating to functioning, predominantly from a physical perspective, whilst stroke

sufferers themselves frame their progress using activities that bring meaning to their life before stroke. A study by Folden (1994) of twenty stroke survivors builds on the understanding of stroke from the lived experience, and suggests that stroke patients may be able to accept that a return to their pre-stroke life is impossible. They are able to set personal goals to help them undertake some of their pre-stroke activities. This definition of recovery differs significantly from that suggested by Doolittle (1992), where a return to pre-stroke life was the predominant personal recovery target.

The study undertaken by Häggström, Axelsson and Norberg (1994) attempted to elicit both the experience and future expectations of twenty-nine people living with stroke. The methodology included the use of photographs depicting either an individual eating independently or being helped to eat by a nurse to facilitate narration. The ten study informants had been living with stroke for at least 18 months, were receiving some form of continuing care in an in-patient setting and had been involved in a study of post-stroke eating problems. Four themes were identified: uncertainty; sadness and mourning; gratefulness, hope and satisfaction; and isolation. Importantly the study demonstrated the importance of ensuring the integrity of an individuals' life history after stroke, as extensive reinterpretation may be required for successful adaptation to sequelae.

Participants included in the studies of Folden (1994) and Doolittle (1992) were tracked for no more than six months, and may not, therefore, reflect important aspects of long-term recovery. Doolittle's (1992) study concentrates primarily on the point of discharge from an institutional setting to the patient's home. Whilst the studies undertaken by Mumma (1986) and Häggström, Axelsson and Norberg

(1994) did include people who had been living with their stroke for over six months, both studies were cross-sectional in design. This may reduce their ability to describe the 'process' of stroke recovery from the perspective of an individual patient. This is a similar criticism of an albeit larger study of forty stroke survivors by Pound and Gompertz (1998) who explored patient perceptions at ten months post stroke. All of the cross-sectional studies reported here are also heavily dependent on the ability of patients to recall events over the course of a complex recovery path, and may therefore lack significant depth.

Another study identified for this review utilised a phenomenological approach to elicit the experiences of stroke during the course of the disease (Nilsson, Jansson and Norberg, 1997). Ten informants who had suffered a stroke within the preceeding three months were included. Each informant was interviewed twice. The data were contextualised by the deductive application of a theory of developmental crises (Erikson, 1982). Whilst there are similar reservations about the ability of the research design to capture the process of stroke recovery, the overwhelming totality of stroke, and the struggle to grasp the implications of stroke are evident.

An exploratory study (Burton, 2000b) which attempted to address some of the temporal weaknesses in earlier research, was undertaken in the early stages of the development of this thesis. The aim of this study was to identify the lived experience of recovery from stroke from the patient's perspective. Specifically the issues and themes identified by patients to describe their own recovery over time were sought. The philosophical framework adopted in the study was phenomenology, as an understanding of the 'meaning' of life with stroke was

sought. It assumed that the underlying essence of this meaning would emerge through the reflective description of an informant's own world (Roche, 1973; Ricoeur, 1976; Strauss and Corbin, 1990). Verbal expression of this description could be fixed in text, where the meaning intended by the speaker can be located (Ricoeur, 1971; Klemm, 1983). The principles of grounded theory methodology were used to elicit and clarify meaning from interview transcripts. The strength of grounded theory relates to the process of the constant comparing of emerging concepts within the data to guide further data generation and comparison (Glaser and Strauss, 1967). Emergent concepts are thus grounded or embedded in the data.

The research aim required that a tracking approach was adopted where informants were followed over a significantly longer time than previous studies undertaken in this area. A decision was taken, therefore, to limit the number of informants with a view to undertaking more in-depth and long-term study. A total of eight people, two of whom refused consent, were approached for inclusion in the study. All those approached had been admitted to the rehabilitation unit of a district general hospital in the north-west of England with a diagnosis of first stroke.

All informants were interviewed individually in hospital following their initial admission following a stroke. Initial interviews were informal and unstructured to enable maximum free expression (Morse and Field, 1995), with informants being asked to tell the story of their stroke. Further data was collected at monthly intervals for at least one year. Follow-up interviews were used to explore issues raised at earlier interviews, and to explore new issues as they arose.

Emerging issues in stroke recovery

In general terms, the exploratory study showed that recovery from stroke involved restructuring and adaptation in all aspects of an individual's life (Burton, 2000b). Abilities to pursue tasks and activities that had previously been taken for granted presented new challenges, requiring appraisal, considerable effort and learning, and re-appraisal. Social roles were challenged and subject to enforced revision, with once comforting and welcoming environments appearing as potentially hostile territory. The emotional responses to stroke were often extreme in nature, with highs and lows that often appeared to show to the external observer little correlation to the actual situations in which patients perceived themselves. Individual reference frames for recovery were complex and highly specific to each informant. Whereas progress to specific goals or activities could be highlighted by informants, this was set in the context of pre-stroke life activity. It appeared difficult for informants to view modest clinical improvements that had been detailed by health care professionals in a positive light.

Research in this area is underpinned by a standard theoretical framework for health (World Health Organisation, 1946) and therefore has tended to focus on physical, emotional and social recovery (Hafsteinsdóttir and Grypdonck, 1997). Whilst these three recovery themes were evident in the data, the lack of integration of themes appeared to be important. The path of recovery from stroke reported by informants was extremely varied in the types and severity of physical, emotional and social problems encountered, and the personal implications of these problems. The process of restructuring of life after a stroke appeared to incorporate a number of physical, social and emotional issues that varied as an

individual adapted to their individual circumstances and contemplated the implications of their stroke on their future lives.

For the purposes of this analysis, each aspect of patient health will be described independently as issues in recovery. As such it may be difficult to stress the interdependence of many of the issues which will be highlighted. A summary of key issues that have influenced the strategic agenda of this thesis will therefore be included at the end of the chapter.

Issues in physical recovery

The physical effects of stroke can be extremely varied, and have been shown to depend principally on the site of the precipitating cerebral incident (Speech and Dombovy, 1995). The classical physical symptom is a unilateral weakness; other symptoms can include sensory and visuoperceptual disturbances, incontinence, dysphasia and dysphagia. Physical recovery has been described in a number of ways, from either a bio-medical or rehabilitative viewpoint (Speech and Dombovy, 1995). Bio-medical models of recovery focus on the viability and process of neuronal recovery, whereas rehabilitative models describe physical recovery in terms of performance in activities of living, usually pre-determined by health-care professionals.

In Burton's (2000b) study, informants generally initially viewed their stroke as an intensely personal experience, although there appeared to be a tendency to view the physical effects as being detached from their body as a whole. The profile of

physical recovery is, although complex, similar across other studies included in this review.

The nature of stroke onset has been well described, where stroke sufferers have identified a complete loss of control, or complete disability, although clinically the stroke involved only part of the body (Doolittle, 1991; Wyller and Kirkevold, 1999). Health-care professionals have tended to regard a stroke as neuronal in nature, and tend, therefore, to refer to a one-sided paresis or weakness.

In the UK, stroke patients should be admitted to hospital given the strong recommendations for admission in the National Clinical Guidelines for Stroke (Intercollegiate Working Party for Stroke, 2000). The most recent estimate of the hospital admission rate for stroke patients is 85% (Stroke Association, 1999). All patients in the exploratory study were admitted to hospital as a result of their stroke and received rehabilitative care and therapy. After admission, stroke patients often continued to perceive a worsening of their condition, despite being fully awake and alert. A strong sense of disappointment that this was happening even though patients were in a hospital environment and were receiving care and treatment was reported.

The first steps towards recovery are usually experienced in terms of increasing sensation, or progress towards goals, which are usually set by professionals (Burton, 2000b). There are however significant differences in the way that individuals experience initial recovery, for example, improvements in speech, sensation and movement, dictated usually by the physical effects of their stroke. At different times throughout their recovery, many patients experience periods

when they feel that their recovery was halted (Burton, 2000b). A common feature of the path of recovery from stroke described by Doolittle (1991) is periods of stability in physical functioning, described as 'plateau periods'. For most this tends to be perceived in one of two ways - either that their existing level of function was the best that it could be, or that their condition as a whole was worsening. What is clear, however, is the lack of preparation that patients often have for these instances, and the negative feelings this precipitates. The slowing down of recovery is often associated with feelings of despondency and frustration, and evoked reflections on pre-stroke life. The weak correlation between tangible, or observed physical recovery and general perceptions of quality of life has also been demonstrated (Wyller and Kirkevold, 1999), where quality of life tends to be influenced by rather than a consequence of physical recovery.

The long-term nature of stroke and recovery from stroke was strikingly evident in Burton's (2000b) study where the sample reported that all new problems and situations which they experienced were mediated by the fact that they had suffered a stroke. The ability to deal effectively with these situations was often affected by the features of physical recovery. When new coping mechanisms had been established and were perceived to be successful, patients felt more able to do things even though the clinical level of function remained constant. This would suggest that actual adaptation in discrete physical activities is not of prime importance in determining quality of life (Wyller and Kirkevold, 1999). Rather it would appear to be the ability to cope with physical limitations that is valued by patients.

Issues in emotional recovery

Although individuals in Burton's (2000b) study varied greatly, a number of consistent themes were identified in the data that described features of emotional recovery from stroke. The impact of the stroke precipitated a range of emotional responses, with no apparent linear sequencing of responses over time. Rather than a series of emotional hurdles which patients had to overcome, emotional recovery was reactive, un-directional and unpredictable. In the early stages, stroke appears to be experienced in a number of ways, depending on the type of stroke, but evidently with feelings of suddenness and overwhelming catastrophe. The initial overwhelming nature of stroke onset appeared to precipitate feelings of immense uncertainty in patients. Individuals felt unprepared for their stroke: they feared what was happening to them, and that they were going to die. For those who perceived a worsening of their stroke in hospital, these feelings appeared to be most strongly marked. The development of the stroke left them feeling uncertain about the future.

Transitions in care, and particularly discharge home, can leave patients feeling unable to plan and unsure about the future (Doolittle, 1991; Stroke Association, 1994; Hart, 1999). The issues that have the capacity to precipitate negative emotional reactions during the immediate period after discharge have been captured by Doolittle (1991; 1992), and can include all or some of the following:

- perceived withdrawal of therapy and abandonment, with no hope of further recovery
- lack of understanding of the roles of new community staff

- a challenge to the personal meaning of the social environment, from safety at home to an environment of obstacles

Uncertainty at this time can often be perceived as extending into the future, when responses to problems or crises are difficult to visualise or anticipate (Burton, 2000b). It is unsurprising therefore that this aspect of stroke services has consistently been highlighted as wanting. An evaluation of a community stroke service, undertaken from a medical anthropological perspective, supports the recognition of uncertainty as an important area on which nurses might usefully focus their efforts in developing the care of those affected by stroke (Hart, 1998).

Hope appears to be a major feature of emotional recovery in the first few weeks after stroke, although this may often relate to making a full recovery from the disease (Burton, 2000b). Nilsson, Jansson and Norberg (1997) identified that hope may be important due to the potential for rapid and spontaneous recovery during the first few weeks after stroke: any early recovery can help to reinforce the possibility of full recovery in time. Progress towards goals set by professionals appears to be important in helping patients to be hopeful about recovery (Lawler, Dowsell, Hearn *et al*, 1999), although this may be challenged by the reduction of professional rehabilitation input after discharge home where patients may no longer have daily access to therapy services (Burton, 2000b).

All patients in Burton's (2000b) study reported a perceived loss of control over their bodies and their individual circumstances, and these feelings were anticipated for aspects of their future lives. Although physical loss could be attributed to a specific and discrete functional activity, this can often be translated by patients to a total loss in a major area of an individual's life, and may reflect

the overwhelming nature of stroke. It is interesting to note that as recovery progressed, some patients appear to focus on positive aspects of their life over which they felt they had control.

In the early days of their stroke, particularly in those who experienced a stroke in evolution, the loss of control appeared to relate to uncertainty about both the immediate situation and the future. Some patients can feel resigned to accepting a passive role in interaction with professional staff, particularly in the early stages of their stroke. This appeared to be mediated by perceptions of the importance of knowledge held by the professionals who were working for them. Feelings of needing help and direction to perform mundane tasks, such as dressing and sitting, provoked negative reactions in all patients in the exploratory study. During later recovery however, the focus of control has been shown to relate to feelings of being dependent on others (Cox, Dooley, Liston *et al*, 1998).

The loss of control associated with the aftermath of stroke, both in physical and social activities of life, can appear to provoke a strong sense of frustration (Burton, 2000b). This linkage between control and frustration appeared to be most strongly related to the physical effects of stroke, with frustration often being directed towards the parts of the body affected by the stroke. Patients often appear to reinforce this frustration by making comparisons with their pre-stroke life (Doolittle, 1991; Wyller and Kirkevold, 1999; Burton, 2000b).

Issues in social recovery

It is clear that stroke can have profound implications for all aspects of a patient's social world. Balances in family and social networks can be disrupted: patients in Burton's (2000b) study expressed concern and highlighted difficulties in re-defining their perceived contribution to social and family life. The perceptions of others within a patient's social network have also been shown to indirectly influence perceptions of quality of life. In particular, low expectations of recovery held by others, even when unfounded, can impose a restriction in involvement in social activities (Wyller and Kirkevold, 1999).

The exploration of intimate relationships has tended to receive relatively little attention in the literature, with a focus on the perceived stresses of caring for a patient at home. Where intimate relationships have been studied, these appear to have deteriorated in approximately 15% of cases (Field, Cordle and Bowman, 1983; Anderson, 1992). This figure may however represent the social norms of the age group predominantly affected by stroke.

Many patients report that their roles and responsibilities were threatened by stroke, most notably in areas of work, finance, family and social networks. Although perceptions varied between each individual, patterns can be recognised involving the continuous appraisal and re-appraisal of social role (Burton, 2000b). Re-appraisal does not necessarily imply an acceptance of the new situation, rather than an adjustment of role. Often these adjustments are evaluated in terms of pre-stroke life, and only rarely in terms of a positive step on the road to recovery.

Patients in a number of studies referred to feeling as though they were isolated or stuck in a cage: the cages ranged from their bodies, to the hospital and their homes (Pound and Gompertz, 1998; Burton, 2000b), where references to isolation were often accompanied by feelings of frustration and anger. Waiting appeared to be a key feature of this isolation: waiting for help, waiting for family and friends to come.

The long-term nature of stroke was evident in Burton's (2000b) study where all informants reported that they would not be able to forget their stroke, and that it would be an important issue for the rest of their lives. They felt that the stroke would have an impact on all aspects of their future lives. It appears that often patients can view the 'real' work of recovery as commencing when professional input has been stopped. This issue was reinforced in a comprehensive study of coping strategies at ten months post-stroke undertaken by Pound, Gompertz and Ebrahim (1999), who identified the following coping strategies actively employed by patients

- mobilising informal support
- creating new ways of doing things
- taking things more slowly
- beginning the process of relearning
- exercising, and
- covering up.

Inspection of the detailed descriptions of these coping strategies strongly suggests that patients took responsibility for reorganising their social worlds to take account of their health and social care needs. This study succeeds in challenging any assumptions that passivity is a necessary consequence of stroke, and

highlights an important area into which professional development can develop. It is unfortunate that much of that expertise remains untapped.

Professional input has also been viewed by patients as being artificial, where the context of therapeutic activity that was designed to help them undertake specific activities in hospital bears little resemblance to patients' own home environments (Hawkins, 2002; Burton, 2000b). The clinical environment differs substantially from the reality of patients' own social environments. Patients can feel that they receive little support in facilitating the adaptation of skills learned with staff in the hospital to their own home (Hart, 1999). A key finding from some of these studies would suggest that even when skills in a physical activity are re-mastered after therapy, the social meaning of that activity is lost (Burton, 2000b). This issue is succinctly captured by Pound and Gompertz (1998 p343) who identify that "it is not just the ability to conduct an activity or not, but also the quality of the activity which is important" when referring to the redevelopment of social activities.

Summary

Whilst many of the studies referred to in the chapter were small in nature, they each provide different and interesting insights to the worlds of those people who are directly affected by stroke. Often in the clinical arena this perspective is difficult to identify and appreciate for obvious reasons. Nevertheless if a patient focus is to be adopted in the development of sensitive and relevant stroke services, then this perspective is worth considering. Understanding how patients experience illness would appear to be an essential pre-requisite to the development of appropriate strategies to facilitate recovery.

Most studies which explore the perceptions of stroke patients have tended to describe recovery using an incremental linear model. Doolittle (1992), for example, details recovery as phases which relate to the time frame of her study. As a result, her interpretation of recovery from stroke can be seen to infer a two-stage model comprising acute and rehabilitation phases. The limitation of this approach, and any other similar approach, is that it supposes a normal path of recovery, with phases of stroke that have a core content. Application of this description of recovery to the development of stroke rehabilitation services necessarily focuses attention on the physical domains of recovery within a time-frame largely dictated by the boundaries of professional service.

Burton's (2000b) study described the experiences of recovery from stroke into the long-term by tracking patients for at least twelve months. Whilst the descriptions of some experiences relating to the early stages of stroke reinforce those of other researchers, the nature of individual definitions of recovery and its on-going nature may require a re-appraisal of existing models of stroke service provision. This study suggested that stroke is an intensely personal experience, involving the rebuilding and restructuring of an individual's world. The real work of rehabilitation described by patients was the translation of learning from the institutional setting to their home environment, which was often attempted alone without recourse to professional help or advice. The social context of recovery was extremely important where the focus of recovery was enabling participation in the social world through adaptation and the development of coping skills, rather than improvement in discrete physical function alone.

The complex nature of recovery and the range of possible stroke sequelae identified in this study highlights the considerable challenge that stroke sufferers and their carers can face. Rehabilitation programs must equip stroke sufferers and their carers with the support, skills and knowledge to shape their future lives in a meaningful and fulfilling way. Surveys undertaken by a patient advocacy group have been shown to indicate that there is much to be done in improving the appropriateness and utility of existing service provision (Stroke Association, 1994). The content of the most recent strategies for the development of services in stroke would suggest that these issues remain pertinent today.

Rather than focusing solely on acute and rehabilitation services, new strategies that reduce existing boundaries of service provision that help patients and their families adapt to life with stroke need to be explored. It would appear that any new strategy should include at least three features:

- the co-ordination of service provision from an over-arching perspective that considers the consequences of stroke from onset into the long-term
- the expansion of clinical interventions aimed at the development of coping and adaptation skills, and
- a focus on the social context of recovery after stroke should be recognised.

This may require the imaginative integration of hospital and community rehabilitation services, for example through hospital out-reach or community in-reach, to enable them to be able to respond flexibly to patient and carer need. Identifying and disseminating the skills developed by stroke patients may play a significant part in these developments.

The analysis in this chapter would suggest that there are potentially significant differences in how patients and professionals tend to view stroke and its consequences. These differences will be explored through the prevalent theoretical frameworks that underpin the organisation and delivery of stroke services.

Chapter 3

Theoretical Perspectives on Stroke Care

Introduction to the chapter

Current health policy stresses that it is essential that evidence of the clinical effectiveness of stroke rehabilitation interventions provides a benchmark for decision making in clinical practice. It is equally relevant however to understand the theoretical perspectives that underpin current stroke service provision. These perspectives are important in determining the focus of services, the goals of health care intervention, and the role that those affected by the disease play in their own recovery. In doing so the acceptability and utility of services can be considered, and services developed accordingly. The previous chapter has indicated that there may be differences between health care professionals and those affected by stroke in the way that recovery from the disease is viewed.

Chapter Two explored some of the literature that seeks to describe the experiences of those directly affected by stroke. This chapter incorporates a critical overview of the broad theories that underpin the assumptions, values and beliefs that influence current clinical practice in stroke rehabilitation. This critique will include new and emerging theories of rehabilitation which may have the potential to assure the utility of services, in addition to their clinical effectiveness. Utility will be explored by comparing the key findings from patient experiences research to the themes that emerge from theories of rehabilitation. The chapter will conclude with the suggestion that the Corbin and Strauss Chronic Illness Trajectory Framework may be a useful theoretical framework to underpin the development of new interventions in stroke rehabilitation.

Traditional models of illness

The predominant model of illness that implicitly pervades much of UK health care focuses clearly on aetiology, pathology, and associated signs and symptoms (Robinson, 1988; Halbertsma, 1995). Pawlson (1994) maintains that the acute simple disease model is essentially curative, where a positive outcome is demonstrated at the anatomical or physiological level. As such, the role of the patient is as passive recipient of treatment, which is usually of short duration. The model emphasises the role of the individual in describing disability, and determining recovery from disabling illness. Whilst this model of illness has undoubtedly underpinned many of the successes in modern health care, its uncritical use may have negative consequences. This is particularly the case where the profile of a disease has an environmental, psychological, or social aspect (Beardshaw, 1988).

Alternative models of chronic illness

There are substantial differences between the traditional model of illness and the chronic complex illness model proposed by Pawlson (1994) where disease is seen to be caused by multiple, contributing factors, with biological, psychological and sociological consequences. The relationship between professional and patient is characterised as active and continuous, where the focus of care and treatment may be on relief from and adaptation to disease consequences rather than cure alone. Shifting the focus of treatment in chronic illness away from cure requires an understanding of how patients view their illness, and the meaning of physical and other limitations (Pawlson, 1994; Joachim and Acorn, 2000). Unfortunately few

documented strategies have been identified which explain how the integration of this perspective with the judgement of health care professionals may be undertaken.

The practical implications of a shift in focus from acute to chronic models of disease are also reflected in the development of a model of rehabilitation proposed by Robinson (1988), which included a distinction between short-term and long-term rehabilitation. This distinction is important as it focuses attention on the practical issues of rehabilitation delivery in current health care policy. In the UK, rehabilitation tends to be of a fixed duration, where the patient has the maximum opportunity to benefit from therapy, usually in terms of physical recovery. This may best be witnessed in the description of intermediate care strategies in the National Service Framework for Older People (Department of Health, 2001a). Whilst this strategy recognises the need for responsive and flexible services to facilitate effective rehabilitation, it is recommended that intermediate care be of no more than six weeks duration. The empirical basis for this specification is unclear.

Rehabilitation would appear to be relevant to patients with both short and long-term illness, although there are essential differences in application (Robinson, 1988). These are summarised in Table 3.1. The long-term model of rehabilitation recognises that the response to illness, which is behavioural, may not be directly related to the disease antecedents (Collier, 1990). The social element of rehabilitation is therefore as important as the physical. These ideas are captured by Robinson (1988 p340) who states that the rehabilitation process 'is very broad and encompasses social as well as physical factors – the aim is a 'social cure' as much

as a 'physical cure'. The objective (of rehabilitation) is thus to achieve as normal a life as possible, in which a major goal is to restore viable social functioning'. In practical terms this approach to rehabilitation requires a significant degree of attention to be placed on the social meaning of physical activities to individual patients. As a consequence there has been a growing interest in social models of disability to underpin the development of new approaches to rehabilitation (Hinton-Walker, 1993; Northway, 1997; Nolan, 1998).

Social meaning is a central feature of the social models of disability, where disability is 'the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on a equal level with others due to physical and social barriers' (Finkelstein and French, 1993 p28). There are however coherent criticisms of the social model disability, not least in the fact that by implication it dismisses the role of trauma or disease that may be important in influencing the life of a person with disability (Oliver, 1996).

The literature tends to suggest that the consideration of disability is a dichotomy, focusing on either the individual or the environment. Northway (1997 p740) for example suggests that 'if (disability) is viewed as a problem which an individual faces....(nursing) action will focus on seeking to promote individual adjustment to disability. In contrast, if disability is seen to arise as a result of social, physical and economic barriers then nursing action will focus on seeking to remove or reduce such barriers'.

A compromise has been proposed (Goodall, 1995) that recognises the importance of both individual and environmental factors in determining personal disability.

Whilst this model fails to demonstrate clearly the role of health care services in addressing these two types of factors, it does demonstrate that any intervention targeted to an individual patient must take account of the environmental milieu in which it is implemented. For example, the benefits of supporting patients to renegotiate activities that have social meaning, such as shopping are limited if transport links to a given community are poor. These issues are reflected to some degree in the international theoretical frameworks used to explore the wider consequences of disease.

The International Classification of Impairment, Disability and Handicap.

The predominant framework that currently underpins a significant proportion of rehabilitation services in the UK is the International Classification of Impairment, Disability and Handicap (ICIDH) (WHO, 1980). This framework is composed of four key concepts: disease, impairment, disability and handicap. These concepts can be interpreted as a linear causative model, where stroke, as a disease, can cause specific physical and neurological symptoms or impairments. These symptoms in turn result in functional deficits, or disabilities, which consequently handicap an individual's ability to maintain their wider social role and function (Badley, 1995). The purpose of rehabilitation then is to return the person to their social world by reducing symptoms and disabilities.

Although it has been proposed that the ICIDH framework concepts are considered to be inter-dependent rather than causative in nature, the application of the framework to diagnosis, treatment, the measurement of health and the evaluation of the outcomes of alternative rehabilitation interventions has also been advocated

(Halbertsma, 1995). This would, however, imply the legitimate consideration of each of these concepts as outcomes of rehabilitation in their own right. In adopting such a reductionist approach, the ability of the framework to address the complexity and diversity of the experience of a disabling illness such as stroke may be lost.

Whilst application of the existing ICIDH framework to stroke focuses attention on the wider consequences of illness, it has two further limitations. Firstly, the framework does not emphasise the wide range of behavioural and environmental factors that are important in shaping the incidence of, and recovery from, stroke. For example, socio-economic status, age, education and/or training, and personality/psychological make-up have been shown to affect recovery (Speech and Dombovy, 1995). Secondly, consideration of the framework concepts as causative in nature can encourage a diagnose-and-treat approach to rehabilitation (Dickson, 1996), where the aim is to facilitate recovery that allows the patient to progress through care settings and to home.

Wade (1992) maintains that implementing this model requires the following:

- a shift in the focus of health care intervention from pathology to handicap over the duration of a treatment episode
- increasing awareness of the environment in which recovery and adaptation occurs
- treatment should be aimed as close to pathology as possible
- assessment should only focus on one level of the framework
- assessment of handicap is personal in nature and will be loaded with personal values and priorities

At first inspection the first and third items appear to be contradictory: focusing treatment at the pathological level reinforces the dominance of acute biomedical care, where other care has value only after treatment to cure pathology has failed. Whilst there is no intention of underestimating the importance of biomedical advances in the management of stroke, the relegation of supportive care designed to promote coping rather than cure to a low priority, low status activity is unacceptable given the problems and deficiencies identified by people affected by stroke.

A new version of the ICIDH framework has been disseminated, the International Classification of Functioning (ICF), which shifts the focus of the framework from impairment to function (World Health Organisation, 2001). It is speculated that the revised framework will go some way to reduce the limitations of its predecessor by highlighting the often negative impact of societal and environmental factors that affect an individual's participation in the social world. Whilst a targeted search of electronic databases would suggest that the revised framework remains largely unexplored in either research or practice, it is worth considering the implications of its major constructs.

The major difference of the ICF from the earlier version is the focus on the 'components of health' rather than the 'consequences of disease'. In this respect, the ICF produces a matrix by which the health of an individual can be described. The matrix is constructed in two parts: functioning and disability, and contextual factors. Functioning and disability focus attention on the relationship between bodily structure and function, and engagement in the social world. In the ICIDH

the link between impairment and disability was, by implication, causative. As the ICF seeks to describe health states rather than classify individuals, the relationship between impairment and disease is dynamic in nature and often indirect. Impairments of body function or structure require some cause, but the cause may not sufficiently explain the experience of impairment. The second part of the ICF framework, which focuses on contextual factors, can be used in some way to explore the relationship between the two.

The ICF includes two main types of contextual factors that are important in shaping the health of an individual with a potentially disabling illness: environmental and personal factors. Environmental factors are easier to identify and represent the physical, social and attitudinal features of an individual's world. These factors can operate directly at an individual level, or indirectly through social structures. This feature of the ICF demonstrates the integration of both traditional and social models of disability in influencing recovery.

Traditional models of disease and disability do not pay significant attention to either the wider consequences of disease or the degree of disability 'felt' by an individual. Their rejection however has the potential to disregard how the background of an individual's life, including coping mechanisms, fitness, education and experience, can influence health. Although they are not described in detail and therefore related only loosely to the framework, the ICF does however acknowledge the importance of personal contextual factors in shaping recovery. Whilst very little of the relevant literature includes reference to the importance of personal factors, their inclusion represents a significant advance on a debate

which appears to have polarised traditional and social models of illness, disability and recovery.

Application to stroke

In clinical practice and health care policy, stroke is usually described in terms of either its acute phase or in terms of rehabilitation. This description fits most neatly into the traditional, acute orientated theoretical framework for disease that underpins much of modern health care. This framework can be witnessed in the focus on physical function as the target of rehabilitation, and the predominance of measurable performance of activities of living in outcome evaluation studies (Granger, 1985).

The limitation of the use of this framework in reflecting the chronic and complex consequences of stroke are apparent, not least in its ability to reflect the concerns of those directly affected by the disease. Viewing stroke in its traditional phases can seek to ensure that specific components of care and treatment may be delivered in the most appropriate way. For example, highlighting the social meaning of activities in hospital is clearly difficult in a hospital environment. Neglecting the full range of dimensions of recovery can however reinforce the boundaries of current health care provision, and reduce the effectiveness of health care from the patient perspective.

In the previous chapter, the critique of research exploring the experience of those affected by stroke identified the importance of the social context of recovery, where patients were engaged in constructing some form of meaningful life after

stroke. Clearly the success of this engagement must be mediated by both environmental and personal factors, as demonstrated in the ICF. The discourse of recovery from stroke appears to consistently highlight the relevance of the disease itself, often in terms of physical symptoms. In addition, the disease appears to be referred to as a significant life event, capable of determining future life styles and patterns, as well as determining benchmarks for the assessment of recovery by patients themselves. For these reasons, neglecting the importance of the disease itself by over reliance on a social model of recovery would appear to be naïve. The theoretical development of stroke patient care requires the integration of medical, social and environmental models of disability, where the biography of the patient is critical to successful rehabilitation.

This thesis proposes that the Corbin and Strauss Chronic Illness Trajectory Framework (hereafter referred to as the trajectory framework) has the potential to shape a new approach to rehabilitation that may enhance the experiences of stroke patients and their families (Corbin and Strauss, 1992). Similar theoretical frameworks can be found in the literature that include aspects of the trajectory framework, in particular the temporal element of chronic illness (for example Rolland, 1988; Collier, 1990). The trajectory framework has however been advocated for use in stroke rehabilitation (Nolan and Nolan, 1998), and initial exploratory studies of its utility have been encouraging (Burton, 2000a).

The Trajectory Framework

The trajectory framework, which purports to describe the experience of chronic illness, has evolved during thirty years of research and observation of practice.

The framework as a grounded theory, was developed from an extensive research programme on dying, and refined in studies that included a range of settings and patient groups (Corbin and Strauss, 1992). Since its development the trajectory framework has been applied to a number of patient groups: cardiac illness (Hawthorne, 1991), cancer (Dorsett, 1992), multiple sclerosis (Miller, 1993), diabetes (Walker, 1992), and elderly patients with chronic illness (Robinson, Bevil, Arcangelo et al, 1993).

The central concept of the framework is a trajectory, or illness course. For individual patients this course represents the cumulative effects of a disabling illness including physical symptoms, and the impact of the illness on an individual's social world, challenging perceptions of self-identity, termed biography. Although individual trajectories can only be mapped retrospectively in light of responses to illness, a prospective view of a trajectory can be based on the knowledge, beliefs, values and experiences of both patients and professionals alike (Thorne and Robinson, 1988). The key to the utility of the framework lies in the assumption that although each individual with a chronic illness experiences the disease process in a unique way, there are common phases which involve changes in health status and intervention need (Table 3.2).

The first stage in a trajectory (pretrajectory) occurs before the onset of symptoms, and consequently before a formal diagnosis is made. This emphasises the importance of illness prevention within a framework for managing chronic health problems. When signs and symptoms appear (trajectory onset), these can pose a significant threat to the physical, social or psychological integrity of an individual (crisis phase). The onset of symptoms may precipitate a period of illness that

requires active intervention, usually in an in-patient setting, to prevent the worsening of symptoms, or the prevention of complications associated with the effects of the illness (acute phase). Where intervention is effective, a period of stability may be reached which will require varying degrees of intervention to maintain individual health (stable phase). An individual will, however, experience challenges to their recovery either directly or indirectly associated with their illness which require a reappraisal and adaptation of interventions, usually without admission to a hospital setting, to promote coping and stability (unstable phase). Responses to these challenges to recovery will at some point however, be unsuccessful, and the patient's recovery may deteriorate (downward phase) to such a point that the patient is terminally ill.

The phases of an illness trajectory do not represent a rigid framework for the linear consideration of a patient's response to illness. Each phase for example may include several sub phases which include movement in either direction along a trajectory which can be of considerable duration. This dynamism reflects the continual nature of adaptation that characterises living with chronic illness (Locker, 1983; Chilman, Cox and Nunnally, 1988). Whilst the trajectory phases reflect the long-term nature of living with a chronic illness, the inclusion of the 'downward' and 'dying' phases may be seen to imply that death is an inevitable consequence of chronic illness, emphasising the physical component of individual health. The goals of care for people with chronic illness should however relate to the maintenance of more holistic interpretations of health, including the management and amelioration of symptoms.

The trajectory framework includes a number of related key constructs, including trajectory projection which represents a vision of an individual's illness course. The details of this projection will to some extent depend on the perspective, role, knowledge, experience and attitudes of the person constructing it (Thorne and Robinson, 1988), and therefore multiple projections will exist for individual patients. A trajectory scheme is established on the basis of these projections, and will include an agreed strategy for management. A range of factors that may be important in influencing the success of a trajectory scheme have been identified, which to some degree reflect the environmental and personal factors described in the ICF. Reference is made to trajectory management, or the process by which the illness course is shaped, as the means to 'shape the overall illness course, control and immediate symptoms and handle disability' (Corbin and Strauss, 1992 p17).

One of the advantages of the trajectory framework over the ICF is the structure it provides for the consideration of personal factors. In the context of the trajectory framework, biography, like trajectory, is a temporal construct, representing an individual life course. As a theory for clinical practice, much of Corbin and Strauss's (1992) paper is focused on the concept of trajectory and trajectory management. This part of the theory has the most obvious benefits for practice, providing a map for recovery, and the integration of services over time. Implicit in the paper however is the notion of biography as a target to which trajectory-based care should be aimed. Stroke has the potential to disrupt all aspects of an individual's world, therefore challenging their individual biography.

The purpose of stroke rehabilitation nursing within this framework would broadly appear to be to manage a patient's illness trajectory with reference to the

biographical effects of stroke. In practice this requires both the acquisition and use of in-depth knowledge relating to an individual's biography through active participation on the part of the patient and family, and importantly, the provision of rehabilitative interventions geared to the restoration of independence. In this way professional intervention can be appropriate to the individual. The importance of considering biography is reinforced by Nolan (1998), where re-negotiation of past, present and future biography may be an appropriate goal of health care intervention. According to Corbin and Strauss this may include helping patients come to terms with the adjustment of biographical and social dimensions of stroke, to encourage coping and adaptation (Corbin and Strauss, 1992).

Corbin and Strauss (1992) identify three processes through which stroke affects the self: *coming to terms*, *every-day life activities* and *limitations management*. *Coming to terms* reflects the adaptations that are required to redefine the self after a disabling event. The physical impact of the disease is recognised both in the level of ability an individual has in performing *every-day life activities*, and in *limitations management*. This refers to the changes and adaptations required of individuals to undertake those every-day activities. As such the trajectory framework would appear to emphasise the personal response to a disabling illness such as stroke, neglecting the importance of features of the wider environment that can shape an individual response to disability emphasised in the ICF.

The major advantage of the trajectory framework however is the challenge it makes to the traditional neuronal/functional model of stroke (Speech and Dombovy, 1995) to reflect the long-term nature of stroke. It acknowledges the

importance of learning to live with stroke as a continuous process, unbounded by the notions of acute and rehabilitation phases of recovery. Whilst this feature of the trajectory framework will reflect the issues raised by patients in qualitative research, it does however raise some key concerns. Increasing the timeframe over which the consequences of stroke are considered will necessarily increase the complexity of health care services which have the potential to influence a patient's recovery path. For example, the final phase of the trajectory framework is dying, which requires the provision of different types of services, including palliative care, which are not normally associated with mainstream stroke rehabilitation practice. In addition, increasing complexity in services can result in a cumbersome service where there is a real potential for those affected by stroke to 'fall through the net' (Hart, 2001).

As a mid-range theory in nursing, the trajectory framework provides only general guidelines for clinical practice. Corbin and Strauss (1992) recognise that the framework should provide the foundations for the development of clinical interventions and services, and that, when applied to specific diseases, some problems with application may occur. It is in the spirit of this sentiment that the framework has been used to underpin the expansion of the nursing contribution to stroke rehabilitation services. There are key messages from the trajectory framework that stress the importance of the biographical impact, and the long-term nature of stroke consequences and recovery which provide a useful reference point to evaluate stroke rehabilitation nursing.'

Implications for nursing practice

As a chronic complex model of illness, the trajectory framework has considerable potential as a model for stroke rehabilitation services. It focuses attention on the chronic nature of many of the symptoms of stroke, and the physical, emotional and social consequences of the disease. Whilst the trajectory component of the theory is clearly located at the individual, the inclusion of both the conditions influencing management and biographical aspects of the theory mean it may also be sensitive to the environmental factors highlighted in social models of disability.

Implementing the trajectory framework into clinical nursing practice would, at least, include the following:

- ensuring a focus on the complete trajectory of stroke by increasing the importance given to health promotion and stroke prevention
- attention to the social and biographical needs of stroke patients
- the provision of supportive interventions designed to keep recovery from stroke on trajectory course
- that an agreed vision of the overall trajectory of stroke is used as the basis for rehabilitation and service planning

Implementing the trajectory framework as a theoretical framework underpinning the stroke rehabilitation services may have the capacity to address some of the existing limitations of services highlighted in patient-focused research. Its relevance to current nursing practice, and the strategic agenda for the development of nursing care, must however be considered if implementation is to be achievable.

Short-term rehabilitation	Long-term rehabilitation
Technique-centred	Patient-centred
Professional as controller	Professional as co-ordinator
Patient passively complies with goals	Patient actively involved in goal setting
Hospital based	Community based
Focus on impairment	Focus on handicap

Table 3.1. Comparison of short and long-term rehabilitation¹

¹ Adapted from Robinson (1988)

PHASE	DESCRIPTION
Pre trajectory	Occurs prior to the onset of disease; the preventative phase with no signs or symptoms
Trajectory onset	Signs and symptoms first appear; the diagnostic period
Crisis	Life threatening situation, requiring emergency / critical care
Acute illness	Associated with hospitalisation for management of active illness
Stable phase	Symptoms that are controlled by a treatment or therapy regime
Unstable phase	Symptoms that are not controlled by a treatment or therapy regime
Downward phase	Deterioration due to inability to manage unstable phase, characterised by increasing disability or problem presentation

Table 3.2. The stroke trajectory.¹

¹ Adapted from Burton (2000a)

Chapter 4

Therapeutic Nursing in Stroke Rehabilitation

Introduction to the chapter

The thesis has constructed an argument that the delivery of appropriate and effective stroke rehabilitation services lies in ensuring the full range of concerns and needs of stroke patients and carers are addressed. By considering stroke as a two-stage disease process, the current theoretical perspectives that underpin the traditional approach to the management of stroke services would appear to do little to facilitate this aspect of recovery. As such there is a substantial research and development agenda to enhance the appropriateness and utility of stroke rehabilitation interventions from the perspectives of those affected by the disease. As stroke care is a multidisciplinary enterprise, this agenda is relevant for all professional groups. For the reasons given earlier in the thesis, it will however continue to be developed from a nursing perspective.

This chapter will present an overview of the nursing role in stroke rehabilitation services. In particular, the capacity for nursing to develop, implement and evaluate interventions which seek to enhance the utility of stroke services will be considered. As the volume of empirical research that is specific to rehabilitation nursing in stroke is limited, the chapter will commence with a consideration of the role of rehabilitation nursing in general. Where research on nursing role has been undertaken in stroke, this will be synthesised using the findings of an earlier study undertaken in the developmental stages of this thesis (Burton, 2000c). The chapter will detail an emerging framework of therapeutic nursing in stroke rehabilitation, by considering the relevance of theories of nursing therapeutics. The chapter will conclude with a description of nursing role characteristics that articulate the framework in clinical practice.

Rehabilitation in the nursing literature

Generally, the literature presents a complex picture of the nature and purpose of rehabilitation nursing with an array of often conflicting models and frameworks (Nolan, Booth and Nolan, 1997). There is however, a clear agenda emerging which emphasises the importance of social and psychological aspects of rehabilitation, in addition to promoting physical recovery. For example, Waters (1996 p.242) describes rehabilitation nursing as 'the whole process of enabling and facilitating the restoration of a disabled person to regain optimal functioning (physically, socially and psychologically) to the level that they are able or motivated to achieve'. Although this description would emphasise the nursing contribution to stroke rehabilitation as an holistic enterprise, the realities of the clinical environment can mean that this definition is at best optimistic (Tamm, 1999). Institutional care settings remove patients from their social worlds, thereby eliminating many of the established social networks and coping strategies that may be important in facilitating recovery from illness. Where the illness experience fails to be represented by the acute disease model, these networks and strategies are even more important. As such nursing may only ever be able to offer a 'best' effort in providing truly holistic care.

An early paper containing the viewpoint of the nurse as *rehabilitator par excellence* (Henderson, 1980) appears to contain all the major themes that feature in the debate surrounding the nursing role in stroke rehabilitation. This debate appears to continue to the present day (Nolan, Booth and Nolan, 1997). Henderson's (1980) paper addresses a wider agenda than rehabilitation alone: the combination and potential conflict between the technical or scientific, and

humanistic aspects of nursing care. The reference to rehabilitation appears to capture the central features of humanistic practice that should be, according to Henderson, at the centre of nursing practice in all clinical fields: the ability to develop and use a deep understanding and empathy of an individual's world to enhance the effectiveness and consistency of care. This knowledge may be used to develop this 'best' approach to holistic care by making interventions as sensitive as they may be to the needs and circumstances of individual patients. Henderson (1980) however provides very little information on what actually constitutes rehabilitation nursing.

A description of a generic rehabilitation nursing role has recently been summarised in a systematic review commissioned by the English National Board for Nursing, Midwifery and Health Visiting (ENB) (Nolan, Booth and Nolan, 1997). The review was not specific to stroke, and included a range of diagnostic groups where rehabilitation was thought to be a significant feature of nursing care. The review identified five domains of clinical practice that characterise the nursing role in rehabilitation:

- physical well-being (including care of the skin, nutrition and hygiene)
- a specialist role in continence and care of the skin (Waters and Luker, 1996)
- creating and sustaining an environment for rehabilitation
- reinforcing the input of other professional groups
- a 24 hour presence (Waters, 1987)

Although the review was extensive, little information is given on the quality of individual studies identified in the search strategy. Indeed the lack of empirical evidence to support these domains is evident. The breadth of the review necessitated a low proportion of studies being obtained for critical appraisal. As a

consequence, perhaps, the review focused usefully on areas of potential for the development of the nursing role in rehabilitation, rather than identifying the role itself. The review does, however demonstrate the complexity and multiplicity of perspectives, foci, processes and roles that nurses fulfil or address in the delivery of rehabilitative care.

Whilst general agreement of the nursing role as manager or co-ordinator of multidisciplinary rehabilitation appears to be developing (O'Connor, 1993), the lack of a research base for specific nursing interventions like the maintenance of continence or skin care is evident. In addition, the five identified domains of clinical practice do little to define a coherent therapeutic contribution, demonstrating that a therapeutic role for nursing remains elusive. The emergence of nursing research that seeks to understand the human response to stroke (Doolittle, 1992; Folden, 1994) suggests however that the development of patient and carer coping strategies is likely to be a key area for nursing practice development. For example, Catanzaro (1993) maintains that the goal of rehabilitation nursing is to help individuals with a disability to return to optimal effectiveness in daily living, and that cumulative abilities in discrete activities of living enables participation in the wider social world. Consequently, rehabilitation is focused on the social processes of adaptation and negotiation between the individual and their environment. The nurse in rehabilitation then has a therapeutic role concerned with facilitation of this social process to enhance the individual response to a debilitating illness such as stroke.

Whilst this description of rehabilitation is useful in drawing attention to the wider aspects of stroke recovery, the application of a social model of rehabilitation to

the prevalent pattern of stroke nursing services may be problematic. Nurses tend to provide rehabilitative interventions with stroke patients in institutional care settings (Gibbon, 1994), which have only limited capacity to reflect the realities of the social environment which patients come from, and return to. The naïve application of social models of rehabilitation nursing therefore has the capacity to precipitate the development of well-meaning, but artificial and unrealistic nursing interventions, which in turn may have negative consequences for patients and carers.

From a direct clinical perspective, Gibbon and Little (1995) attempted to develop nursing practice for stroke patients in hospital using action research. Their study required a frank analysis of baseline nursing practice from which the team could move forward. Specific issues were identified in the relationship between nursing and physiotherapy, and in particular the knowledge held by nurses of therapy techniques and their application to individual patients. Perceptions of the futility of stroke rehabilitation were identified, inevitably leading to the low prioritisation of stroke patient care. A profile of study interventions were tailor-made to facilitate the development of stroke patient care from the baseline, including a tutorial programme, nursing documentation system, clinical guidelines, and communication strategy to facilitate multidisciplinary collaboration. In this way, stroke nursing was expanded to encompass systematic and objective patient assessment and goal setting.

Tensions do however appear to exist between active and other components of nursing care. This issue is mirrored by the findings of a comprehensive literature review specific to stroke (Kirkevold, 1997), which described two dimensions of

the nursing role in stroke rehabilitation: the provision and management of the context for effective rehabilitation, and the provision of specific therapeutic interventions. Whilst reviews of the literature can be beneficial in determining current professional knowledge, their quality depends on the validity of the individual studies that have been included. This issue does not appear to be addressed in the review, limiting the usefulness of the review findings.

Kirkevold's (1997) review was, however, underpinned by an earlier study of experienced nurses working in a specialised stroke unit (Kirkevold, 1992). Interviews and observation identified four therapeutic functions or domains in stroke rehabilitation nursing

- an interpretive function that helped patients and families understand the implications of stroke
- a consoling function in providing emotional support
- a maintenance function to ensure that patients attain the best possible 'state' for therapy, and finally
- the integration or translation of therapy, where nurses help patients to assimilate discrete skills or activities learned in formal therapy into meaningful self-care or social activities.

The review attempted to validate these four functions by exploration of their congruence to the research base. Stroke rehabilitation studies published between 1989 and 1995 were identified and mapped according to their clinical focus. The review demonstrated that generally there is a dearth of literature available to support the validity of this framework, and that there is a pressing need for clarification of the nursing role in stroke rehabilitation. Whilst Kirkevold's work

provides a useful benchmark for consideration of the nursing role in stroke rehabilitation, relatively little empirical work has been undertaken in the UK.

More recently, the role of the nurse in rehabilitation defined by the UK's Royal College of Nursing specified five nursing functions (Royal College of Nursing, 2000). These functions, with examples provided in the original text are

- restorative (maximising independence and physical function)
- educative (teaching patients and other staff)
- enhancing daily life (relieving pain and ensuring adequate nutrition)
- teamwork (administrative and supervisory responsibilities)
- supportive (psychological and emotional support)

Whilst this was essentially a policy document, and aimed at older people's nursing, there are similarities in this model of nursing role and the general issues identified in this review of selected literature. Unfortunately the definition provides very little information on what the therapeutic nature of this role is. A supportive function is probably closest to the ideas of humanistic practice espoused by Henderson (1980), but the identification of psychological or emotional support is naïve, simplistic, and fails to reflect the intricacies of balancing motivation, knowledge, power and respect in any nurse-patient relationship. Whilst the benchmark provided by Kirkevold's (1992) work is useful, it is essential that empirical research reflects the organisational, social and cultural aspects of UK nursing.

The nursing role in UK stroke rehabilitation

An exploratory study (Burton, 2000c) was undertaken during the developmental phase of this thesis, the aim of which was to explore and describe nursing practice in stroke rehabilitation. A qualitative approach was adopted that enabled a rich description that would make sense of the clinical realities of the nursing role (Morse and Field, 1995). The key tool for data collection was reflection, which referred to the process of subjecting decision-making to scrutiny using established theory, where possible, as a benchmark for comparison. It has been proposed that reflection enables the surfacing of knowledge that evolves from experience in practice (Heath, 1998). It was hoped that by adopting this approach the data would be cognisant of the individual norms and values that precipitated nursing action, rather than a mere regurgitation of current, established theory.

The research site was a 24 bedded rehabilitation unit in a district general hospital in the north-west of England. The unit catered predominantly for people who have suffered a stroke, but also for people requiring rehabilitation after some surgical procedures, for example hip replacements. The unit had close links with a day hospital, and had a range of multidisciplinary professionals formally attached to the unit. The unit was managed by a rehabilitation manager (a senior nurse), supported by a senior staff nurse. Nursing care was organised around a team structure, each team having particular responsibility for a 'bay' of between six and eight patients. Each team was led by a registered staff nurse, supported by a number of staff and enrolled nurses, and unqualified staff. The mix of nursing staff at the time of the study was 60% qualified and 40% unqualified staff who worked as nursing auxiliaries or health care assistants. The difference between

these two groups of staff was contractual in nature, both working in a supportive capacity to qualified nurses. The study sample consisted of all qualified nursing staff (n=13) working in the rehabilitation unit at the research site.

The rehabilitation unit was headed by a consultant physician, supported by a small team of junior doctors. A physiotherapist and occupational therapist were attached to the unit, and provided a number of dedicated sessions to the patients on the unit. Multidisciplinary care was facilitated by case conferences: these occurred weekly and were attended by the full range of professionals who had an input into a particular patient's care. Patients, or their carers, did not attend case conferences. Each professional group maintained their own records, although some therapists principally physiotherapists, recorded assessments in the nursing care plans.

Nurses on the rehabilitation unit were supplied with proformas developed from the double loop model of reflection proposed by Greenwood (1998). After completing questions relating to biographical data, nurses were asked to describe a particular clinical incident relating to the care of a patient with stroke that had been important to them. They were advised to select an issue that had occurred during their last shift in practice, so as to maximise recall. Each reflection commenced with a full description of the incident, and what else was happening around them at the time. They were asked to specify a range of outcomes that they were attempting to achieve and why the outcomes were important to themselves, the patient, the multidisciplinary team and the organisation. The final questions related to alternative courses of action, and the reasons why these alternatives were not adopted. Participants were encouraged to complete a minimum of three

reflections within three months. Ethical approval was obtained from the hospital research ethics committee prior to commencement of the study.

A total of 35 reflections were obtained for analysis. Each reflection was treated as a transcript, and was subjected to analysis using the framework advocated by Burnard (1991). Although this framework was developed specifically for interviews, the process of analysis was appropriate to the type of data generated. Initially, each reflection was read in entirety to aid 'immersion' in the data. Open codes were reviewed and condensed where possible into a coding frame of categories and sub-categories. Reflections were again reviewed using a word-processing package so that the content and context of each sub-category could be collected in separate files. Each sub-category was explored in terms of three elements: nursing activity, patient outcome and the contextual features that shaped the intervention. The coding frame was reviewed and confirmed by an independent researcher.

On completion of the study, the findings were verified using a focus group methodology (Carey, 1994). A purposive sample of four nurses of different grades was drawn from the unit staff to participate in the group. Although including staff of different clinical grades and experience potentially decreases disclosure (Kreuger, 1988), it was felt that representation from the nursing team was required. The group commenced with a discussion about the research methods used to act as a warm-up. The findings of the study were then presented and discussed, followed by closer scrutiny of thematic content. Focus group participants were asked to reflect on the ability of the study findings to reflect the realities of practice.

In essence, three categories that described the nursing role were identified in the study: the nurse as provider of care, the manager of multidisciplinary provision, and the nurse as therapeutic practitioner. Each category was associated with a range of anticipated patient outcomes, and consisted of a number of sub-categories described in terms of nursing interventions. A number of contextual factors were also identified in the data that appeared to be important in shaping nursing activity within each category. These categories are used to explore and integrate the findings of other empirical studies that have sought to explore the nursing role in stroke rehabilitation.

The Nurse as provider of care

Nurses often tend to see themselves as the principal providers of care for stroke patients, most citing the continual presence of nurses on the rehabilitation unit as evidence for this. The 24 hour presence of nurses for stroke patients can be responsible for the development of an environment that is conducive to rehabilitation (Waters, 1987). However, the structure and delivery of care may not always match this philosophy. A clear and focused analysis of what nurses are actually doing, and why, within these 24 hours is essential to develop and promote the quality and effectiveness of services available. The major theme of the nurse as the provider of care identified in this study related to care activities that were predominantly aimed at the completion of interventions where basic physical needs were provided for, patient safety was maintained and harm to the patient prevented (Burton, 2000c). Often these activities were prescribed by other professional groups, or were related to nursing policies and procedures, and

established practice regimes. Importantly these tended not to be directly related by nurses to patient outcomes of rehabilitation.

This finding would appear to support the description of physical nursing work that has to be completed in stroke rehabilitation demonstrated by both Waters (1994) and Gibbon (1994). It is encapsulated in the notion of physical care, from which Nolan, Booth and Nolan (1997) suggest that nursing expands in the pursuit of a rehabilitative function. Kitson (1999) refers to these aspects of nursing as 'essential', emphasising the environmental influence of nursing espoused by Nightingale as the bedrock for the development of professional practice (Selanders, 1993). Whilst the importance of these aspects of care cannot be underestimated, it has been acknowledged that the evidence-base to support this aspect of the nursing role is very limited (O'Connor, 1993).

The Nurse as manager of multidisciplinary provision

In Burton's (2000c) study, nurses also described a range of activities that related to the management of patients, including liaising, organising, mediating and planning. These activities were designed to co-ordinate the input of other health care professionals, to promote the well-being of patients and their families, and to enable smooth transitions of care for patients. Co-ordinating the multidisciplinary team from day to day was a key aspect of patient management and involved the strategic planning of patient care. The case conference was identified as the principal process by which important decisions regarding patient care were made. With respect to information, nurses felt they were best placed to provide information relating to patients' general progress, coping and emotional health.

Other information they provided related to the patient's home circumstances and social support. Their perception of patient advocacy related to the depth of knowledge they had developed as a result of their interaction with patients and their carers. Whilst not necessarily having what they saw as ultimate responsibility, they had developed proactive relationships with other health care professionals, and with patients, to facilitate this aspect of their role.

O'Connor (1993) maintains that the managerial aspects of the nursing role implies the role is secondary to the roles of other professional groups, as no specific function is delineated. If, however, nurses do operate in stroke rehabilitation with an holistic awareness that is drawn, as Henderson (1980) would maintain, from 'getting inside the patient's skin', then this does imply a unique function. The nurse would indeed be in the best place to co-ordinate and mediate the contributions of other professional groups to ensure that patient progress is maintained. Gibbon (1999) however demonstrates that the nursing contribution to the development of patient management strategies may be limited, and may only include putting into operation the decisions of therapists. Similarly whilst the importance of this activity cannot be underestimated, it fails to delineate any uniqueness in the nursing contribution to stroke patient care.

The nurse as a therapeutic practitioner

Waters (1994) suggested that quite often nurses *do for* a patient in rehabilitation, but that this does not necessarily help the patient to achieve independence. She cites a number of reasons why this may be so, including the structure of rehabilitative nursing care and multidisciplinary input, and beliefs about

rehabilitation. To explore this issue further, however, requires an understanding of the stated goals of nursing intervention, and the external and internal factors that either precipitated a change in the desired outcome or mode of intervention.

A number of nursing interventions in Burton's (2000c) study suggested a more meaningful degree of interaction between the patient and nurse, the key purpose of which were the development of coping strategies and the maintenance and improvement of well-being. Although some of these activities were related to specific physical activities of living, they tended to be set within a wider context of recovery. Four sub-categories were identified that described this increased interaction: helping, comforting, teaching, and working with the patient and family, and are similar to those identified by Kirkevold (1992). Nurses appeared to value these aspects of nursing care, and were able to describe interventions that were aimed at emotional well-being through physical and emotional coping skills. This type of nursing intervention tended to be underpinned by the development of an inclusive relationship between the nurse and patient and family. Involving the patient in decision-making and encouraging an active participation in rehabilitation has been strongly advocated (Nordstrom, 1980). Although the observable benefits of this approach to rehabilitation may be difficult to determine (Hamrin and Lindmark, 1990), they appear to be both desirable and necessary from a sociological viewpoint (Pollitt 1988).

The focus of nursing interventions on emotional outcomes mirrors to some extent the interpretive nursing function identified by Kirkevold (1997). Although recognising this function is important in helping patients to come to terms with the consequences of stroke, the major focus on Kirkevold's analysis is restricted

to the acute phase of the disease, and does not include the development of coping skills for rebuilding life with stroke identified in the previous chapter. Limited reference to future life with stroke is made however in terms of 'expected trajectory of the disease' during the provision of information to patients and carers as part of the interpretive nursing function (Kirkevold, 1997 p57).

Nurses often cited the importance of positive relationships to help patients come to terms with their stroke, and to help them move on, whilst recognising the important part that family and friends would play in a patient's long-term recovery. Effective communication was seen as key to building relationships to facilitate the gathering of information about social support and circumstances to mediate care planning. Recognition of the psychological sequelae of stroke in practice were particularly evident, with a high priority attached to activities that the nurses perceived to alleviate stress and anxiety, and to promote effective coping strategies (Burton, 2000c). These activities may be identified as specific activities important in their own right, but also indirect activities that were carried out alongside other, more physical, activities.

In recent years the nursing profession has identified potential role expansion to include a range of activities that could be perceived to be the domain of other professional groups (UKCC, 1994). A close partnership with, for example, the physiotherapist was highlighted, with nurses providing and facilitating much of the practice element with patients. This appeared to be a logical reaction to the structural nature of multidisciplinary work of the unit where it was perceived that the physiotherapist had only limited time available for individual patients. Nurses tended to leave the assessment of patients mobility to the physiotherapist, but

continued to work with the patient during her absence. In this sample, nurses maintained that although the therapists worked with patients to develop micro or fine physical skills, their role was to translate these skills into physical function in activities of living. This supports to some degree the findings of other studies that describe the understudy role of nurses to other health care professionals in stroke rehabilitation (O'Connor, 1993), and see the therapist as the expert (Waters, 1994). Whether nursing aspires simply to reinforce therapy or to provide some meaningful context for therapy remains unclear.

As well as providing interventions that maintain and ensure physical integrity for recovery, nurses have been shown to use the knowledge and understanding of individual patients' needs they acquire through working with patients and their carers to shape the multidisciplinary rehabilitative effort. Nursing interventions that were specifically related to the outcomes of rehabilitation were characterised by the nature of the interaction between patient and nurse: a partnership to improve coping, well-being and meaningful activities of living. These interventions included shaping the contributions of other professional groups to individual patient circumstances whilst practising therapy. It may be that whilst nurses carry-on the work of the therapist, patients can be supported to integrate therapy into their care, rather than simply practice it in isolation.

Although nurses would appear to recognise the expertise of other professional groups, there were a large number of instances where nurses felt unsupported in their delivery of rehabilitation. For example in the absence of therapy services, nurses may assess the risk of the patient not receiving an assessment for some time, and instituting care based on that assessment. It appears that risk-taking can

therefore used to counter deficiencies in the structure of the delivery of multidisciplinary rehabilitation, to ensure that patients received what was perceived to be appropriate intervention. It appeared, however, that where this does happen, activity may be unsupported by either formal training, or the use of formal assessment tools.

A number of important features of the nursing role are evident which provide understanding and capacity for development of the nursing contribution to stroke services. There is considerable overlap between nurses and other health care professionals that tends to be a product of the organisation of in-patient rehabilitation services. This would suggest that the development of the relationship between nursing and other professional inputs is a product of organisational management, rather than any professional development, or patient-centred approaches to rehabilitation.

Nursing role in stroke rehabilitation

In summary, the nursing role in stroke rehabilitation would appear to be fundamentally concerned with the provision of care, which is technical, managerial and therapeutic in nature (Table 4.1). This care is aimed at a range of patient outcomes that include the maintenance and improvement of health and well-being, and the development of coping strategies. Nurses appear to adopt a range of strategies to help patients achieve these outcomes dependent on a number of factors. There is a core of well established activities that attempt to prevent further deterioration in the patients condition, to prevent harm, and to maintain safety that appear to be 'done for' a patient. These actions appear to infer the

patient as a passive recipient of care and rehabilitation, and tend to be rule, or policy driven. Nursing also appears to have a patient management function which primarily facilitates the co-ordination of therapy and services.

There would also appear to be a range of therapeutic activities however, which promote an active partnership between the patient and nurse. The focus of the partnership is on the achievement of wider outcomes of recovery, including the development of effective strategies which enable patients to deal with the aftermath of stroke. Nursing interventions within this theme would appear to focus principally on education and emotional support. The success of this participative approach to care will be influenced by the perceptions and attitudes of the individual nurse. Participation requires that a non-paternalistic approach to engagement with patients is adopted that acknowledges the priorities and aspirations of individual patients (Cahill 1998). This shift towards patient-centred as oppose to professionally-driven care requires that information, decision-making, evaluation and responsibilities are shared between patient and nurse (Coulter, 1999). This may only be facilitated by an open discussion between nurse and patient, which seeks to narrow the information and knowledge gap between patient and nurse (Cahill, 1996), and that takes into account the potential differences in the type of knowledge and language used by both (Ashworth, Longmate and Morrison, 1992; Guadagnoli and Ward, 1998). Therefore, therapeutic nursing in stroke rehabilitation requires a dialogue between the patient and nurse that recognises the importance of patients' knowledge of their health, and the use of professional knowledge and appropriate language to support patient recovery.

There may be an emerging theme which highlights the practical performance of specific physical activities of living which nurses are able to place in the context of an individual's life. For example, nurses may be able to integrate a patient's therapy interventions into other nursing care activities such as eating or washing, thereby providing some social meaning to practice. Where the restoration of physical function is the primary goal of rehabilitation nursing, clinical practice may be approached in a reductionist manner which builds on a repertoire of discrete skills. This approach may neglect the socio-psychological importance and meaning of physical function as a whole. Although the outcomes targeted by therapeutic nursing in stroke rehabilitation appear to recognise the socio-psychological impact of the stroke or loss of function, more research is required that focuses on the theoretical and practical aspects of the therapeutic nursing contribution to stroke rehabilitation services.

Therapeutic nursing in the nursing literature

The importance of building a model of therapeutic nursing has been recognised in the professional literature (Kitson, 1997), possibly as a consequence of the increased importance attached to the range of health care interventions that are readily identified and assessed, and therefore feature highly in the more bureaucratic school of quality assurance initiatives. There is, understandably, a concern that all too often therapeutic nursing practice may be sidelined by the cumulative effects of nursing role expansion, mostly into the domain of medical practice, and reducing skill-mix in favour of roles whose purpose is to assist qualified nurses. The sheer complexity of therapeutic nursing practice, coupled with the profession's propensity to use an abundance of psycho-social theories to

define different aspects of professional practice may make much of this literature appear impenetrable.

This thesis does not attempt to define a theory of therapeutic nursing in stroke rehabilitation. Rather it will construct a framework using some of the key themes that appear to predominate in the literature on therapeutic nursing, and applying them to stroke rehabilitation. It is important to acknowledge that this analysis does not attempt to denigrate other aspects of nursing such as technological care which have seen dramatic advances (Benner and Wrubel, 1989). The thesis will suggest that each aspect of nursing practice is important and essential to the overall patient experience.

The literature includes practice-driven, inclusive models of therapeutic nursing practice (for example, Buchanan, 1994) where the therapeutic element is identified through the stated goal of care, in this case enhancing quality of life. Whilst in some respects these models are naïve, offering little philosophical, theoretical or empirical support to underpin their development, they are useful in delineating an early distinction between traditional, clinical and therapeutic practice. The goals of therapeutic practice tend to focus on broad psycho-social outcomes rather than physical outcomes indicative of 'cure'. The danger of this broad approach to defining therapeutic practice is however that it may be argued the vast majority of nursing interventions indirectly aim to improve quality of life. Similar reservations can be highlighted about Henderson's otherwise seminal paper on the development of humanistic practice which is defined as the ability of the nurse to 'get inside the skin' of patients (Henderson, 1980 p247).

Work undertaken in the UK demonstrates that therapeutic nursing 'comprised more emotional and personal aspects which enabled (the nurse) to comfort and support the patient' (Kitson, 1984 p258). Close inspection of the development of Kitson's work (Kitson, 1986) demonstrates that her model of therapeutic nursing was at the time closely aligned to an emerging model of geriatric nursing. This model had been developed in response to perceived deficiencies in, and was defined by its difference to, the medical model of health care (Norton, 1965; MacFarlane, 1976). As such, the 'therapeutic' content of this research does not appear to be significantly underpinned by any empirical work. A similar description of the therapeutic nature of nursing was however identified in a more recent UK study (Ersser, 1996). This observational study identified the process of therapeutic nursing as including the following activities:

- interacting and forming a relationship with the patient
- helping with bodily caring
- helping the patient to learn
- influencing the context of care
- being caring

Information on actually how these activities might best be implemented, or the pre-requisites for their implementation is however more difficult to identify.

Ersser's work is grounded in the 'nursing beds' movement in the UK over the past few decades. This movement arose from a perception that the interests of those with chronic and complex care needs may not best be served by traditional models of hospital care provision. Clinical practice for those patients admitted to nursing beds included

- the development of nurse-patient relationships through the provision of personal care
- the development of an environment more representative of the realities of patients' homes
- attention to the provision of information, and
- the provision of comfort (Muetzel, 1988).

Whilst these practice characteristics appear to be representative of the theoretical development of therapeutic nursing practice in the literature, little information on the research used in their development is evident.

Based on the synthesis of sixteen qualitative studies undertaken in an adult population, Sherwood (1997) identified four elements or patterns of therapeutic nursing practice. The first pattern, *healing interaction*, focused on the development of an environment conducive to healing, where nurses physically and verbally demonstrated support, protection or concern. Secondly, *nurses' knowledge*, described the use of knowledge of human behaviour to develop person skills and convey positive personal attributes. Whilst the *intentional response* described the performance of caring activities through clinical skills, what identified this pattern as therapeutic was the focus on the fit between the planned care and the physical and emotional needs of the patient. The fourth pattern, loosely termed *therapeutic outcome*, described objectives of therapeutic nursing practice in terms of patients' sense of welfare and the relationships with nursing staff. Whilst the analysis recognises the importance of direct care-giving by nurses as part of the total health care experience, it is the manner in which this is performed that also appears to be key. Sherwood suggests that 'manner', in this respect, is derived from both theory and an in-depth knowledge of the patient. The

key theme to emerge from this analysis that describes therapeutic nursing appears to be the relationship that is constructed between patient and nurse over time, and the practical use of the knowledge that can be derived from this relationship.

The notion of a therapeutic relationship includes reciprocity between nurse and patient (Ashworth, Longmate and Morrison, 1992; Kitson, 1999), where the nurse uses their 'person' for a given purpose relating to a patient's recovery (Uys, 1980). Whilst the phrase 'uses their person' does little to enhance understanding of what constitutes a therapeutic nursing intervention, a useful taxonomy of cognitive, physical, psycho-social and spiritual features of therapeutic nursing care has been proposed (Uys, 1980 p179). The descriptions of activities that can be located in each of these four themes demonstrates a considerable range of therapeutic nursing interventions.

Cognitive features of therapeutic nursing would appear to relate to understanding and interpreting patient behaviour to facilitate the development of the relationship with the patient. Physical aspects include presence and touch to affect emotional state, either directly or indirectly alongside other nursing activities. Issues of spiritual therapeutic care relate to patient feelings of faith, hope and value. Psycho-social therapeutic care includes the use of teaching, socialising and communication skills to support the patient emotionally in attaining a sense of a healthy and fulfilling life. Examination of the intended outcomes of these interventions demonstrates more consistency. Intended outcomes are clearly located at the level of the patient, and relate principally to perceptions of understanding, acceptance and other psychological attributes.

The notion of a therapeutic relationship in nursing has been particularly influenced by Carl Rogers, who advocated a shift towards the person as the focus of care. Broadly speaking, Rogers' work emphasised the responsibility of the individual in recognising and addressing their own concerns (Rogers, 1976). The role of the nurse utilising a Rogerian approach to the development of a therapeutic relationship is to facilitate this self actualisation (Payne and Walker, 1996). The benefits of using Rogers' theory of nursing include the provision of a focus for holistic practice, by implication at the level of the individual. Similarly to the criticisms of traditional models of disability and their 'individual' focus, there is also a danger however in neglecting the importance of the social pre-requisites for, and consequences of, recovery from illness in an individual affected by stroke.

The importance of nursing as a human interaction has been acknowledged in a number of key nursing theories. Levine (1973 p1) for example states that 'nursing is ... a discipline rooted in the organic dependency of the individual human being on his relationships with other human beings'. The relevance of this approach to defining the purpose of nursing to clinical practice can easily be identified in King's (1981) theory of nursing, and later description of an interaction-transaction nursing process. Here, nursing is 'based on knowledge of human interactions in which a critical human variable (coping) should be of concern in helping those we serve to build collaborative relationships and participate as informed decision makers in their own health care' (King, 1992 p604). Whilst few of the more established models specifically refer to 'therapeutic nursing', Orem (1995 p54) refers to the word therapeutic as being 'supportive of life processes, remedial or

curative when related to malfunction due to disease processes, and contributing to personal development and maturing’.

Whilst it is readily acknowledged that communication skills are essential to the development of a therapeutic relationship with patients, the knowledge required to support a therapeutic relationship has received less attention in the professional literature. The knowledge identified in the models of therapeutic practice proposed by Uys (1980) and Sherwood (1997) focuses primarily on theories of communication and behaviour, where knowledge is used to identify hidden meaning in interaction with the patient. The role of knowledge that is specific to a disease process from either a professional or patient viewpoint receives little attention in the literature. Where research has explored the therapeutic practice element of stroke rehabilitation nursing (Kirkevold, 1997; Burton, 2000c), a knowledge of potential patterns of recovery, and solutions to potential problems that stroke patients may face in the future would appear to be important.

The use of professionally derived knowledge would appear to be critical in defining the difference between therapeutic nursing care, and a general, more diffuse provision of emotional care. Here the use of different sources of knowledge is employed within a professionally bound relationship to enhance a range of patient outcomes, predominantly psycho-social in nature.

In summary, therapeutic nursing would appear to be an approach to clinical practice, located in the development of a clinically useful relationship between the patient and nurse. Critical to the development of this relationship is the degree to which it is reflective of, and responsive to the concerns and experiences of the

person experiencing the disease. As an approach to practice, therapeutic nursing cannot be viewed as a discrete entity in its own right, and will often be witnessed in conjunction with other aspects of patient care. It will however be intended to promote broadly psychological outcomes relating to acceptance, well-being, and coping, and in the construction of a meaningful social world after disease.

A framework of therapeutic nursing in stroke rehabilitation: key themes

An operational definition of therapeutic nursing relies on the ability to identify observed behaviours that are identified within the theories of therapeutic nursing (Burd and Marshall, 1963; Curl and Koerner, 1991). Whilst acknowledging the difficulty in identifying aspects of this relatively abstract concept, the taxonomy advocated by Uys (1980) does succeed in providing a benchmark for development. The taxonomy suggests the target of therapeutic nursing to be patient perceptions of their recovery from illness, with a focus on the generation and adaptation of meaningful social worlds in which patients emotional health can be maintained. What would appear to be critical to the operationalisation of therapeutic nursing is the ability to use combinations of those interventions identified in the taxonomy. The selection of those interventions is highlighted as an intellectual function, chosen to 'fit the (nurse's) personal style as well as the patient's needs' (Uys, 1980 p180). What would appear to be a defining feature of therapeutic nursing care is the relationship between the content and purpose of the nursing intervention.

Whilst therapeutic nursing practice in stroke rehabilitation may be delivered in the present, its purpose is to support the development of recovery strategies for the

future. These strategies will principally include learning to cope physically and emotionally with the effects of stroke. As such the performance of therapeutic practice in stroke rehabilitation requires extensive skills in the application of theories of communication, but also knowledge of the full profile of disease and recovery processes. It is likely that this knowledge is both formal, based upon the biological sciences and traditions that construct contemporary nursing, and the tacit knowledge that evolves through experience and critical reflection on clinical practice (Meerabeau, 1995).

Therapeutic relationships by their very nature are restricted by the organisation of care delivery. Whilst the creation of therapeutic relationships may be facilitated by the degree of contact that patients have with nurses during an in-patient episode, even specialist nurses in stroke appear to have limited capacity to work across the traditional boundaries of health care (Burton, 1999). Central then to the expansion of the therapeutic nursing contribution to stroke rehabilitation will be an ability to develop and follow a therapeutic relationship through the maze of health and social care services.

The transmission of knowledge between both patient and nurse is a key feature of therapeutic nursing practice in stroke rehabilitation, and is underpinned by the development of a therapeutic relationship. In this way, educative and supportive interventions to develop these coping skills will typify therapeutic nursing practice in stroke rehabilitation. The literature would demonstrate however that therapeutic practice is not an isolated nursing function. Rather therapeutic interventions may be implemented alongside other aspects of nursing care, as an adjunct to other aspects of the nursing role.

It is acknowledged that this analysis merely represents an emerging framework of therapeutic nursing practice in stroke rehabilitation. It fails to acknowledge other aspects of the nursing role that are receiving attention such as the relationship between nursing and physical therapy (Forster, Dowsell, Young *et al*, 1999). Exploratory work would indicate that the principal agenda for this type of development is cross-boundary working rather than the profile of patient outcomes identified in the purpose of therapeutic practice.

Therapeutic nursing in stroke rehabilitation and the Trajectory Framework.

The core elements of a framework of therapeutic nursing in stroke rehabilitation are summarised in Table 4.2, and include the following:

- focusing on the concerns and priorities of those affected by stroke rather than professional priorities for recovery
- using the nurse-patient relationship as a medium for education and support
- focusing on adjustment to the consequences of stroke, through the acquisition of effective coping skills in those affected by stroke
- facilitating the development of meaningful social worlds by those affected by stroke as a significant outcome

The performance of therapeutic nursing would appear to require well developed communication skills, and an understanding of the process of recovery from disease. These features of therapeutic nursing would appear to be consistent with the features of clinical practice using the trajectory framework outlined in the previous chapter.

The temporal dimension of recovery was shown to be strongly articulated in the trajectory framework, highlighting the long-term nature of chronic illness. The potential of the trajectory framework to provide a useful alternative to existing models of stroke rehabilitation, focusing on individual recovery paths, has been proposed. Specifically its use in practice may have the potential to bring the perspective of those affected by stroke closer to service planning. The description of therapeutic nursing practice in stroke rehabilitation described so far has not directly referred to the longitudinal nature of recovery from stroke. However there is an implicit assumption that time is required to support the development of a meaningful social world. If this is accepted to be a significant outcome of therapeutic practice, then a prospective vision for individual recovery is required in planning care within a therapeutic approach.

The trajectory framework acknowledges to some degree the role of the patient in defining their recovery from disease through the concept of biography, where the 'aspects of self can be affected or altered by illness or its management, thereby changing the person's life course' (Corbin and Strauss, 1992 p19). In this way, the effects of stroke are located within the world of the patient, and will impact on the ability to maintain social, emotional and physical roles. The research into patient perceptions of recovery from stroke cited earlier in this thesis would suggest that pre-stroke biography is also important, providing the reference frame in which personal recovery can be evaluated. Both aspects of biography reinforce the importance in maintaining a strong patient focus in the provision of therapeutic nursing care.

‘Supportive assistance’ is the phrase incorporated in the trajectory framework which refers to the nursing response to the consequences of stroke, emphasising the importance of teaching and counselling. The complexity of the relationship between educative and supportive interventions and the priorities of those affected by the disease are acknowledged where the ‘central feature of (nursing care) consists of the choices made about how to live biographies and carry out the activities of daily living so that they might be compatible with the prevention and management of illness’ (Corbin and Strauss, 1992 p20). By implication, the implementation of therapeutic nursing interventions requires a careful balance to be struck between the aspirations of patients, and the realities of potential recovery paths.

The factor that delineates therapeutic nursing in stroke rehabilitation from other more diffuse aspects of emotional support would appear to be its purpose. Rather than merely providing comfort, although this is important in itself, the provision of educative and supportive interventions in therapeutic nursing is targeted to specific patient outcomes. These outcomes are broad and patient-focused, and are concerned with the development of coping skills which enable meaningful engagement in a patient’s social world. The biographical element of the trajectory framework reinforces this as a dominant outcome domain of therapeutic nursing practice.

Summary

This chapter has constructed a framework for therapeutic nursing in stroke rehabilitation by the integration of nursing theory and observational studies of the

nursing role in stroke rehabilitation. The framework focuses attention on the provision of educative and supportive interventions designed to promote recovery based on the realities of living with the effects of stroke. Therapeutic practice rests in the development of the nurse-patient relationship, requiring the use of communication skills and potential recovery paths by nurses. The framework is cognisant of many of the criticisms of traditional approaches to stroke rehabilitation which may not reflect the social and environmental consequences of disability. As a nursing theory, the chronic illness trajectory has the capacity to underpin the development and implementation of therapeutic nursing in stroke rehabilitation in two ways: by focusing attention on the longitudinal and biographical nature of recovery from stroke, and reinforcing the fact that a key task for those affected by stroke is learning to live with its aftermath.

Type of nursing intervention	Description
Care giving	<p>Aims to maintain patient safety and prevent harm</p> <p>Tends to be rule, policy or prescription driven</p> <p>Role of patient is as passive recipient of care</p>
Care management	<p>Aims to co-ordinate and mediate multiprofessional input</p>
Recovery facilitator	<p>Aims to improve wider outcomes of psycho-social dimension</p> <p>Therapeutic in nature</p> <p>Tends to incorporate educative and supportive interventions</p> <p>Patient focused with patient as an active partner</p>

Table 4.1. An overview of the nursing role in stroke rehabilitation¹

¹ Adapted from Burton (2000c)

Elements of nursing care
Special emphasis on the needs and concerns of individual patients
Emerges from a successful nurse-patient relationship
Supports the development of coping skills and adjustment to the consequences of stroke
Outcome is to facilitate the development of meaningful social worlds by those affected by stroke

Table 4.2. Therapeutic nursing practice in stroke rehabilitation.

Chapter 5

Therapeutic Nursing in Stroke rehabilitation

– A Systematic Review

Introduction to the chapter

The thesis has constructed an argument that nursing in stroke rehabilitation has a discernible therapeutic function, which is characterised by a matrix of educative and supportive interventions with associated outcomes. A central feature of this therapeutic element is the relationship between nurse and patient that develops during an episode of care.

The multidisciplinary of the total stroke rehabilitation enterprise has been acknowledged from the start of this thesis. The view that collaboration depends on a shared understanding of the unique value of each professional group reinforces the need for research that examines their respective contributions. Whilst all health care professionals will develop some form of relationship with patients over time, these relationships will principally be shaped by the sphere of professional responsibility. Historically, the nursing profession has ascribed a caring, therapeutic function to its members, which it has been slow to articulate and study with much degree of rigour.

In this thesis a therapeutic function in stroke rehabilitation nursing, which serves a specific therapeutic purpose, has been articulated from the professional literature. This first part of the thesis will continue with an exploration of the impact of this therapeutic function on patient outcomes, identifying which aspects of this therapeutic function have been studied, together with any gaps in the evidence-base. The results of this review will support the development of the framework of therapeutic nursing in stroke rehabilitation, that is cognisant of both theory and current research, to guide the development of clinical practice.

Systematic review - overview of methodological principles

The archetypal literature review has been a traditional feature of health care development, informing the development of research questions and designs (O'Connor, 1992). There are however a number of weaknesses in relying on traditional methods in identifying both best clinical practice and gaps in the knowledge base requiring further research. Developments in statistics, most notably meta-analysis, coupled with increasing scrutiny of techniques for evidence-based practice, have highlighted the increasing importance of systematic reviews in health sciences. Meta-analysis refers to the “statistical manipulation of results of separate studies, the purpose being summarisation and synthesis” (Abraham, Shultz II, Polis *et al.*, 1987 p128). By implication, meta-analysis refers to a pool of studies to be summarised numerically, and thus incorporates a search or review of the literature. It is the rigour of the review process that is the distinguishing feature.

The principal weakness of a traditional literature review is the selectivity of the research that may be incorporated into the synthesis. In contrast a systematic review includes an explicit search strategy to ensure that individual studies that are identified and reviewed are representative of research that has been undertaken. This requires targeted searching of multiple electronic databases, hand-searching other databases and journals, and strategies to locate unpublished research (Abraham, Shultz II, Polis *et al.*, 1987). This last feature of a systematic review is essential to limit the impact of any positive publication bias (Rosenthal, 1978).

The methodological features that should underpin a systematic review have been outlined in guidelines published by the National Health Service Centre for Reviews and Dissemination (NHS CRD, 1996). Broadly speaking, these include the following activities

- specification of the intervention of interest
- search strategy and sampling
- quality assessment
- data extraction and synthesis

The essential features of a systematic review include the *a priori* specification of the clinical intervention of interest in terms of a precise operating definition. As the purpose of a systematic review is to remove the ‘insignificant, unsound, or redundant deadwood in the medical literature from the salient and critical studies that are worthy of reflection’ (Mulrow, 1994 p597), this emphasises the need to identify all relevant research through the use of multiple sources of information (Clarke and Stewart, 1994). These include

- multiple electronic databases
- hand-searching of key journals
- grey literature, to identify research published in formats or sources not usually used within health care
- conference proceedings
- consultation with leading researchers, and
- secondary references from papers identified from the previous sources (Dickersin, Scherer and Lefebvre, 1994; NHS CRD, 1996).

Several checklists can be found in the literature that can be used to assess the quality of studies that have been identified. From those studies that meet the inclusion criteria, and where there is evidence that thresholds for methodological

quality have been reached, then data can be extracted systematically and combined thematically or statistically.

In ascribing to these standards for systematic review, the final product has the capacity to conclusively indicate the relative merits of a clinical intervention, within the context of the best available evidence. In relation to clinical effectiveness, as systematic reviews facilitate the statistical combination of data across studies, they are able to support the analysis of larger pools of data. By implication, this combination can increase statistical power (Mulrow, 1994), so 'reducing' the 'real' effect size of a clinical intervention that can be detected. Systematic reviews of the literature may therefore be particularly useful for studies of interventions that have only a moderate effect size.

Whilst the specification of clinical effectiveness is an important aim of the systematic review, and explains to some degree their perceived importance in health care, they also present other opportunities. These include the assessment of the generalisability of research findings, and the consistency, or otherwise, of relationships between research variables (Mulrow, 1994). The pooling of studies will enable the examination of trends in clinical effectiveness across a wider range of health care populations and settings than would otherwise be possible (Peto, 1987).

This approach to the review of scientific literature is not without criticism however. O'Connor (1992) rightly identifies the considerable amount of time and resources that are required to undertake a review to these standards. Two further concerns are identified, relating to low specificity in the early stages of a review,

and the requirement for some *a priori* knowledge about the literature to ensure that sampling is comprehensive. These points are important, but perhaps do not reflect the belief that a systematic review can be seen as research in its own right rather than merely a preparatory phase in the construction of a research protocol (Abraham, Shultz II, Polis *et al.*, 1987). As in the examination of research tools in a pilot study, consideration of a search strategy and search terms is also required in the early stages of a review to ensure that sensitivity and specificity are enhanced.

Application to modern health care and nursing

Whilst methodological advances have focused attention on the possibilities of systematic review and meta-analysis, the growth of the evidence-based agenda in health care has been instrumental in defining their importance in clinical and political decision-making. Specifically, the principal framework or hierarchy used in evidence-based health care to define the strength or quality of evidence has awarded systematic reviews of randomised controlled trials priority status.

An early review of the use of the meta-analysis technique in the nursing literature maintains that a key issue for engagement of the profession was the paucity of trials (Smith and Stullenbarger, 1991). This issue is reinforced by Cullum (1997) who maintained that the limited number of systematic reviews in nursing perhaps to some degree mirrors the profession's reported reluctance to engage with the clinical trial agenda. The nursing literature can be characterised by persistent debate about the relative merits of alternative paradigms in the development of nursing knowledge. Whilst the intensity of the debate may not have been matched

by the actual performance of nursing research, the debate has raised questions about the relevance of clinical trials and systematic reviews for all aspects of nursing care. This thesis will argue in later chapters that new models of health care evaluation, which recognise the political nature of rigorous 'real world' research have the potential to address some of these persistent criticisms.

Systematic Review

The thesis has constructed an emerging framework for therapeutic nursing in stroke rehabilitation. As a methodology then the systematic review has the potential to explore the congruence between the development of therapeutic nursing practice as a theory and clinical research, by identifying those aspects of the theory that have been subject to empirical validation, and highlighting aspects of the framework for future testing. In addition, where empirical work has been undertaken, a systematic review has the potential to synthesise the cumulative evidence of clinical effectiveness.

The principles of systematic review outlined in the National Health Service Centre for Reviews and Dissemination (NHS CRD, 1996) has been used to underpin this review.

Review Aim

This review aims to explore how the therapeutic aspect of the nursing role has been developed and evaluated in the stroke rehabilitation literature.

The principal interest in systematic reviews would appear to focus on the identification of clinical or economic effectiveness of health care interventions. By default, the performance of a systematic review can highlight gaps in the evidence-base, and the relationship between theory and clinical practice. This examination of theory is particularly relevant when the intervention of study is complex, and where it is feasible that only distinct parts of the theory have been implemented and evaluated in clinical practice. The objectives of this systematic review therefore include the following:

- to identify which aspects of the framework of therapeutic nursing in stroke rehabilitation have demonstrable benefits
- to highlight which aspects of the framework have no empirical basis
- to assess the overall congruence between the framework and the stroke rehabilitation nursing research base

Summary of theoretical underpinnings

This thesis has constructed a framework of therapeutic nursing in stroke rehabilitation. The key features of this framework are that therapeutic nursing interventions in stroke rehabilitation focus on

- the wider psycho-social consequences of stroke, reflected in the concerns and priorities of patients
- the nurse-patient relationship as a medium for education and support
- adjustment and the acquisition of effective coping skills in those affected by stroke
- the development of meaningful social worlds by patients as a significant outcome

Review question

What is the best available evidence for the effectiveness of therapeutic nursing interventions in stroke rehabilitation?

Criteria for considering studies

Types of participants

Studies must relate to interventions delivered to any group of patients with a diagnosis of stroke.

Types of interventions

The framework for therapeutic nursing in stroke rehabilitation has been used to articulate the rules for determining the types of interventions which will be included in this review.

Firstly, therapeutic nursing in stroke rehabilitation is located in the nurse patient relationship. Any study for inclusion in this review must therefore articulate that the intervention is delivered by a qualified, registered nurse, working with a patient.

Additionally, for inclusion a study must explore any interaction which includes any, or all of the following

- The provision of information and advice which responds to individual patient

needs and priorities

- Other interventions identified and delivered by nurses where the primary stated aim of intervention is the promotion of coping and adjustment to the consequences of stroke.

Types of outcome measures

The framework focuses on the importance of patient sensitive outcome domains, which relate to emotional health and social well-being. Studies of suitable interventions which include the following types of outcome measures were included.

- Measures of global health (including quality of life)
- Specific patient-focused indices (for example, locus of control, perceived coping, social support)
- Social activation, or the performance of activities of living
- Depression and other aspects of mental health

Types of studies

Studies that are consistent with the MRC (2000) guidance on testing the effectiveness of complex interventions, namely exploratory controlled trials or pragmatic randomised controlled trials, were included in the review.

Search strategy

The search strategy included the following sources of published studies:

Electronic databases

- Medline
- CINAHL
- Cochrane Database of Systematic Reviews
- EMBASE
- Allied and Complementary Medicine
- PsychINFO

Other electronic sources of information, including the CENTRAL database were not searched. In addition however, the total Steinberg Collection of nursing theses and dissertations held by the Royal College of Nursing Library in London was also reviewed.

An intervention-based strategy was used to search electronic databases, using both controlled vocabulary and free text terms. This was combined with elements of the Cochrane Stroke Group subject-specific strategy to identify potential studies. The strategy was modified to suit individual electronic databases.

For Medline, the following diagnostic group search terms were used:

- Exp Cerebrovascular disorders/
- Stroke\$.tw.

- Cerebrovascular\$.tw.
- Transient Ischemic attack\$.tw
- 1 or 2 or 3 or 4
- Hemiplegia/
- (Aphasia or dysphasia or hemianopia).tw.
- (Hemiplegia or hemiparesis).tw.
- 6 or 7 or 8
- 5 or 9

Professionally specific search terms were

- nursing as a free text term.

Pilot work on identifying suitable descriptors or mesh headings indicated that more specific terms may have had low sensitivity. Additionally, the pool of studies initially identified was limited to those published in English as no funding for translation was available.

Personal contacts to the following researchers in the field were also undertaken in an attempt to identify suitable unpublished studies:

- Dr. Bernard Gibbon (University of Central Lancashire)
- Professor Caroline Watkins (University of Central Lancashire)

Both have access to the UK Stroke Rehabilitation Research network.

Review methods

The validity of the protocol was established by peer review, including the clarification and agreement on the terms, definitions and processes of the review.

Searches were undertaken as specified in the protocol by one reviewer (CB). The initial 'numbers of potential papers identified from the different sources during the initial trawl is detailed in Table 5.1.

All available abstracts were initially assessed for inclusion using the following criteria

- Evidence of an evaluative study including a control group
- Evidence of a therapeutic nursing focus

All papers that showed evidence of both criteria were obtained for closer review.

A blinded reliability check of a random sample of 10% of the papers (n=168) identified in the search of the Medline database was also performed by an individual with an interest in evaluation research in nursing. All abstracts of potential papers identified in the original search were forwarded with the review protocol. Total agreement was obtained with decisions to include or reject individual abstracts..

An assessment of each included study for content and quality was made using an assessment form developed for this review. Papers that fulfilled the quality criteria were then mapped according to the nature of the study intervention and the method of evaluation.

Review findings

The design of the search strategy, whilst it was inclusive, reduced its precision, with a high retrieval rate for rejected papers. This is inevitable given the lack of

any strong, established theory of therapeutic nursing in stroke rehabilitation in the literature. For this reason it was decided to report related studies as well as included studies, to assist in the conceptual development of the review topic. Related studies were evaluative, focused to an educative or supportive intervention, or both, but were not located in the therapeutic relationship between patient and nurse. These studies did not therefore meet the criteria for inclusion, and are detailed in Table 5.2. The details of those papers that were included in the review are detailed in Table 5.3.

The related studies that were identified were focused to the following key themes

- Patient and/or carer education (Evans, Matlock, Bishop *et al*, 1988; Pasquarello, 1990; Rodgers, Atkinson, Bond *et al*, 1999)
- Specific stroke roles (Dennis, O'Rourke, Slattery *et al*, 1997)
- Social support (Friedland and McColl, 1992; Grant, 1999)
- Augmented services designed to support early discharge from hospital (Mayo, Wood-Dauphinee, Cote *et al*, 2000; von Koch, de Pedro-Cuesta, Kostulas *et al*, 2001)

The reference lists of reviews of literature or protocols for reviews that were identified in the original searches of electronic database (Forster, Smith, Young *et al*, 2002; Mant, Langhorne, Dennis *et al*, 2002; Knapp, Young, House *et al*, 2002) were also searched in an attempt to locate any secondary references.

No new studies were identified in a review of Medline, EMBASE and PsychLit for non-drug strategies for psycho-social recovery in stroke (Knapp, Young, House *et al*, 2000). Of the four systematic reviews identified in the search of the Cochrane Database of Systematic Reviews, two were deemed relevant, and again

searched for secondary references. This search did not yield any new studies, although it confirmed the use of five related studies, and one included study.

The consideration of related cases is an established stage in the process of concept development (Meleis, 1997) and the identification of related studies was used in this review to facilitate the theoretical development of the review topic. Secondary references were not therefore routinely recorded as related, unless they were also identified in one of the primary sources. For this reason, studies that were included in the Cochrane systematic reviews, and could be considered to be related, are not included in Table 5.2. This principally applied to a review of information giving (Forster, Smith, Young *et al*, 2002) and a protocol for a review of Family Support Workers submitted by Mant, Langhorne, Dennis *et al* (2002).

In relation to studies of information giving in general, Forster, Smith, Young *et al* (2002) conclude that the effectiveness of providing information to those affected by stroke has not been demonstrated. Whilst preliminary evidence demonstrated some potential for information provision to improve knowledge, the translation of this into tangible health gain appears weak. The studies of information-giving included in the Knapp, Young, House *et al* (2000) review reach similar conclusions, although it is evident that information giving in stroke rehabilitation research appears to adopt an instrumental approach (Rodgers, 1995), where it is assumed that the information provided is useful and that patients are receptive. Inspection of these two reviews does not demonstrate that a study of a transactional approach to information giving, including preferences for information content and type has been undertaken as yet.

The study of caregiver counselling and education reported by Evans, Matlock, Bishop *et al* (1988) was included in both the related overviews of literature. The intervention focused on an active approach to counselling, with a focus on the provision of information to support the development of carer coping strategies. The study demonstrated that counselling was significantly better than education alone. Two further related studies were identified in the search strategy for this review which do not appear as included or rejected in either of the two reviews described so far. In a pre-test post-test study of an acute stroke program, which included patient teaching by a stroke nurse specialist, Pasquarello (1990) demonstrated its potential to improve medication and follow-up compliance. The study is weak in design with retrospective data collection, which may attest to its neglect in other reviews. It does however demonstrate the feasibility and potential benefit of including patient education and support in the implementation of an acute stroke program.

From a methodological perspective a strong trial investigating the effectiveness of a multi-disciplinary stroke education program for patients and carers was reported by Rodgers, Atkinson, Bond *et al* (1999). It has not been included in this systematic review as no specific reference to aspects of the framework of therapeutic nursing can be identified. An early report of the study is included in the review reported by Forster, Smith, Young *et al* (2002), although it is surprising that it is not referred to by Knapp, Young, House *et al* (2000). Here, inclusion in the stroke programme was associated with increased knowledge and increased satisfaction with some aspects of the total stroke service, although again this did not translate into tangible clinical benefits. A general summary of the research into information provision in stroke services would be that it can

meaningfully contribute to knowledge attainment in those affected by the disease, and may enhance the overall acceptability of services. It has not, unsurprisingly, been linked to improvements in functional or perceived health.

The stroke family care worker role was evaluated by Dennis, O'Rourke, Slattery *et al* (1997) in a relatively large randomised controlled trial. The intervention was referral to the care worker role whose role was to provide counselling, identify unmet need, and attempt to meet that need from existing resources. Provision of the intervention was flexible, with an ability to respond to individual needs and concerns. The intervention again was associated with increased satisfaction with services, although, rather worryingly, experimental group patients demonstrated increased levels of depression, helplessness and poor social adjustment. It is postulated that the provision of support through this role may have precipitated a passive role on the part of patients, and consequently the profile of negative outcomes. Whilst the authors' criticisms of their study referred to in the paper relate in the main to the practice of pragmatic trials in stroke rehabilitation, such as withdrawals and blinding, the timing of follow-up assessment is also limiting. It is acknowledged in the report that assessment at six months may not have enabled families to demonstrate the establishment of strong coping mechanisms to support recovery.

The provision of social support to stroke patients or their caregivers was studied by Friedland and McColl (1992) and Grant (1999) respectively. The supportive intervention provided to patients by clinical psychologists was underpinned by empirical and theoretical work, and focused on a network approach to social support. This included the identification of individual social networks, and

attempting to enhance those directly where appropriate (Friedland and McColl, 1992). In a moderately sized clinical trial (n=48 experimental group, n=40 control group), any effectiveness of this intervention in terms of a variety of psycho-social assessment tools was not demonstrated. The assessment time frame for this study was again limited, with a maximum of follow-up of three months. Grant's (1999) trial focused however on 'collaboration between a registered nurse and primary caregiver to strengthen social problem-solving skills and help caregivers deal more effectively with the caregiving experience' (Grant, 1999 p255). This was a three group trial where usual support was compared with training in caregiver problem solving with either home visit or telephone support. The study was quite small with only ten patients in each arm of the trial, and the large number of outcome assessments rendered the trial susceptible to Type I errors. Whilst there were no benefits of the training detected in terms of general health, caregiver burden and satisfaction, the group receiving telephone support demonstrated a reduction in depression, together with enhanced perceptions of problem-solving skills and preparedness for caregiving. It is postulated that the flexibility and detachment implicit in telephone support contributed to an ability to objectively appraise the caregiving experience.

The two final related studies refer to services augmented by supportive interventions, although again the therapeutic nursing contribution to the intervention of study was not explicit. Both of these studies relate to the body of literature emerging in early discharge schemes, and may not be representative of the sum of research undertaken in this area. They were however identified in the original searches for this systematic review. Their inclusion as related studies services to contribute further refinement of the notion of therapeutic nursing in

stroke rehabilitation. Both studies refer to interventions where baseline practice was augmented as follows

- ‘prompt discharge’ and rehabilitation focusing on function and social re-integration during the first three months after stroke in the case of Mayo, Wood-Dauphinee, Cote *et al* (2000), and
- ‘early discharge’ with rehabilitation at home for six months (von Koch, de Pedro-Cuesta, Kostulas *et al*, 2001).

It would appear that the general rehabilitation advocated by von Koch, de Pedro-Cuesta, Kostulas *et al*,(2001) was no less effective than traditional approaches to the organisation of stroke services. A targeted rehabilitation program focusing on and within the community did however appear to enhance the translation of learnt therapy to the home setting, contributing to greater re-integration and perceived health.

Included studies

The two studies identified in this systematic review focus clearly on the development of nurse-patient relationships, through the delivery of different interventions by qualified nurses. Both interventions incorporate elements of education and support, responding to the needs of individual patients, with relevant intended patient outcomes.

The study reported by Folden (1993) was undertaken in the United States. The intervention was closely aligned with Orem’s (1995) model of nursing, focusing on ‘helping individuals make decisions about their self-care goals’ (Folden, 1993 p162). In practice, experimental group patients received a nursing intervention

supporting the identification of relevant goals, resources and barriers to the successful achievement of those goals, and an individual action plan. This intervention, termed Guided Decision Making (GDM) was delivered in four sessions over a two-week period. Whilst a protocol for the delivery of GDM was used in the study, inspection demonstrates that implementation of the protocol was flexible. The role of the nurse in the protocol was to support the patient in identifying goals, ensuring relevance and appropriateness, and ensuring viability in the setting of action plans. The study population inclusion criteria included a first stroke requiring rehabilitation, age between 65 and 85 years old, and an expected length of stay of at least 24 days. The report does not stipulate exactly when and where the study intervention was delivered, although it can be deduced that this was during the acute in-patient episode.

The remaining study was undertaken in the United Kingdom by Forster and Young (1996), and focused primarily on the provision of information and advice in response to individual patient need during visits to patients at home. Whilst the trial report does not identify any theoretical base, the term specialist nursing is used to describe the study intervention. A protocol for the delivery of information and advice is provided, but similarly closer inspection of its content, and reports of its implementation demonstrate that flexibility to respond to individual patient needs was possible. Whilst flexibility in the Folden study related to the content of GDM, the Forster and Young study intervention varied both in content and in duration. Here the number of visits scheduled for the first six months was six, although the average was eight with a maximum of nineteen. One visit was scheduled for twelve months after stroke although similarly, the average number of visits was four with a maximum of ten. The study population inclusion criteria

included a diagnosis of acute stroke with a stroke related disability.

Related papers that have emerged from the original trial indicate that the intervention studied by Forster and Young (1996) was designed to improve psycho-social adjustment (Lawler, Dowsell, Hearn *et al*, 1999). It was based on a framework programme, developed in consultation with local stroke patients and their caregivers. It included goal-setting, problem-solving and advice on specific issues (Dowsell, Lawler, Young *et al*, 1997). It is unclear how this profile of interventions was linked to the priorities of patients and carers specified in the development work, or why, at a theoretical level, they would enhance psycho-social health. Indeed the inclusion of goal-setting was interesting given that three out of the five nurses delivering the study intervention refused to implement this aspect of its content. It is clear however that nurses in this study incorporated a whole range of activities, including nursing therapeutics, in their work with experimental group patients. This emphasises the need for a strong theoretical, and practical base to underpin the development of the nursing contribution to stroke care.

The outcome assessment employed in the two studies were quite different. The principal assessment tool used by Folden was the Exercise of Self-Care Agency (ESCA) scale (Kearney and Fleischer, 1979). In addition the Mini-Mental State Exam (Folstein, Folstein and McHugh, 1975) was used for screening purposes. The Revised Barthel Index (Granger and Gresham, 1984) was used to assess functional ability, although the reasons for incorporating this tool into the study design and the resulting profile of scores are not provided. Forster and Young used the Frenchay Activity Index as the principal outcome assessment tool

(Young and Forster, 1992), along with the Barthel Index (Wade, Wood, Heller *et al*, 1987) and Nottingham Health Profile (Hunt, McEwen and McKenna, 1986). This study also assessed carer stress through the General Health Questionnaire (Goldberg and Hillier, 1979). Both studies included a range of demographic variables and process measures.

The selection of outcome assessment tools in both studies is interesting. Whilst perceptions of self-care ability was an obvious choice in the Folden (1993) study, it is unfortunate that perceptions of ability were not more strongly linked to performance. There is however comparative breadth in the choice of assessment tools by Forster and Young (1996). Here the potential to over assess subjects is recognised in the omission of the physical mobility section of the Nottingham Health Profile in lieu of the Barthel Index. This however potentially weakens the study as the Barthel Index assess pure ability, and the Nottingham Health Profile assesses patient perceptions of ability. In addition, the composite score of the Nottingham Health Profile is weighted, albeit equally, across six dimensions. As such, the authors fail to address any threat to validity through this omission.

The strongest study in terms of methodology was the trial of specialist nursing, which was powered to detect a 50% improvement in the regain of social activities as indicated by the Frenchay Activity Index. The trial appears to have incorporated a pragmatic approach to design and an intention to treat approach to analysis. The lack of a subject flowchart means however that the treatment of subjects, and reasons for non-completion are difficult to ascertain. Folden (1993) incorporated a quasi-experimental design with the alternate assignment of the study intervention. The report fails to consider sample size in study design, and

explicitly does not adopt an intention to treat approach to analysis.

The data reported in the Folden (1993) study indicated that group means and standard deviations for the Exercise of Self-Care Agency were similar prior to intervention delivery (Control group 109.18 (12.91); Experimental group 108.92 (10.98). After eight weeks the corresponding results were 115.18 (10.51) for the control group, and 127.74 (11.42) for the experimental group. From the information presented in the paper, this post-intervention data can be converted to 95% confidence intervals as follows: control group 115.18 (111.65, 118.71); experimental group 127.74 (123.90, 131.58). Caution should however be taken with this extrapolation as the samples sizes were small (34 in each group), and no information on the normality of data is presented. From a clinical perspective, the difference in the means is small, some 12 units out of a maximum score of 215 (Kearney and Fleischer, 1979), which significantly limits the practical importance of this study.

Forster and Young (1996) fail to demonstrate any significant effect of their study intervention in relation to improvements in patient outcome, other than for the performance of activities of living when adjusted for Barthel Index score at randomisation. This improvement in performance was most marked at three and six months after randomisation, although differences between the two stratified groups at twelve months were not significant. In addition, analysis of covariance for the full data set demonstrated that there was a significant treatment effect over the full twelve months during which subjects were followed up. When considering the total profile of results, it is difficult to ascertain whether these results represent the identification of a target group for intervention, which Forster and Young

propose, or statistical error. The Barthel Index score is however a strong predictor of recovery from stroke (Wade, 1992), and this would lend strength to their explanation. More research however is required to determine whether the provision of information and advice post-stroke is more valuable in some sub-groups of patients, and what the most effective methods for information transmission are.

Both studies do however concentrate attention on aspects of the framework for therapeutic nursing practice in stroke rehabilitation defined earlier. The role of nursing in both studies is to support recovery from stroke through educative or supportive interventions. The specialist nursing intervention was described as flexible, enabling those delivering it to respond to the individual needs of experimental group subjects. Folden's (1993) study meanwhile provided the development of a process designed to enable patients to address their own needs and concerns. Whilst only limited information is presented on the issues that patients addressed in the Folden study, they appear to be related to activities that were undertaken prior to stroke, the consequences of stroke including emotional outbursts, or care regimes such as anticoagulation. The emphasis of guided decision-making was on the reduction of interference that these issues caused in relation to individual lives.

The temporal dimension of therapeutic nursing is however limited in both the included studies, where only limited opportunity to build on any therapeutic relationship between nurse and patient is possible. Folden (1993) limits her intervention to the acute care period, whilst the Forster and Young (1996) study intervention is provided in the community, by community staff after discharge

from hospital. This is surprising given that one of the key concerns that has been highlighted in patient-focused research is the transition from hospital to home (for example, Doolittle, 1992). There is a need to consider how the organisation of stroke nursing services can best be organised to fully support a therapeutic intent. In particular, no evaluation of an overarching nursing perspective supporting individual recovery paths, facilitating the implementation of a therapeutic approach has been identified.

The validity of a systematic review can be identified in the transparency of its methods for the identification and assessment of all relevant research. There are few systematic reviews available that focus on nursing issues, possibly reflecting the paucity of rigorous research and in particular clinical trials undertaken in nursing. There certainly appears to be a reluctance in the nursing literature to subject much of what might be termed its 'caring function' to evaluation. This necessarily has an impact on the wider understanding, and language of nursing interventions in systematic review. The inclusion of related studies in this review has attempted to ensure that an appreciation of the practical aspects of therapeutic nursing in stroke rehabilitation can be identified.

Conclusions

This review identifies that little attention has been paid in the literature to the rigorous examination of the therapeutic aspect of the nursing role in stroke rehabilitation. This reflects both the paucity of nursing trials, and the lack of strong theoretical work in this area of nursing. Two studies have been identified however that explore different aspects of therapeutic nursing. Folden (1993)

explored the effectiveness of a guided decision-making strategy in promoting perceptions of self-efficacy. The results show that, accounting for methodological weakness, this intervention is a promising and useful addition to the repertoire of psycho-social interventions in stroke management. Guided decision-making can play a key role in helping patients to achieve a sense of personal control and efficacy over their initial recovery from stroke. Whether the intervention is useful in other recovery phases, or whether perceptions of self-efficacy are linked to other aspects of recovery such as functional ability or quality of life is unexplored. Where this intervention is studied in future, additional outcome assessment tools that focus on these issues should be included. Forster and Young (1996) demonstrate that the flexible provision of information in the community after stroke may be beneficial for those patients with mild physical disability in the immediate period after stroke. This finding warrants further attention in a prospective evaluation, focusing specifically on this section of the stroke patient population. No intervention has been identified that includes therapeutic nursing across the profile of recovery rather than within the profile of current service boundaries.

Source	Total identified	Obtained	Results Rejected	Related	Included
Medline (1966 – April 2002)	1684	138	1677	5	2
CINAHL (1982 – April 2002)	688	62	683	3	2
PsycINFO (1887 – May 2002)	11	1	10	0	1 ¹
Allied and Complementary Medicine (1985 – 2002)	191	10	189	1	1
EMBASE (1980 – 2002)	845	25	841	3	1
Cochrane Database of Systematic Reviews (2002)	4	2	2	2 (5) ²	0 (1) ²
Steinberg Collection of Nursing Dissertations (Royal College of Nursing, London)	4	4	4	0	0
				19	8
				Duplicates 8	6
				TOTAL 11	2

¹Earlier Dissertation version of Folden 1993 study

²Identified through secondary references

Table 5.1. Systematic review results.

Author	Year	Intervention	Outcomes	Comments
Forster A., Smith J., Young J <i>et al</i>	2002	Information provision for stroke patients and carers	Inconclusive evidence of effectiveness of current approaches to information provision.	Systematic review under auspices of Cochrane Stroke Group. Secondary references also checked for this review.
Von Koch L., de Pedro-Cuesta J., Kostulas V. <i>et al</i>	2001	Supported discharge and rehabilitation at home	Differences in process, although no differences in patient outcome	Experimental patients did receive additional nursing care after discharge, although the therapeutic focus of that care is not disclosed.
Mant J., Langhorne P., Dennis M. <i>et al</i>	2002	Family support worker	Cochrane review protocol	Protocol only. Secondary references checked for this review.
Mayo NE., Wood-Dauphinee S., Cote R. <i>et al</i>	2000	Supported discharge and rehabilitation at home	Significant advantages for instrumental activities of living and social reintegration	Therapeutic nursing content of home-based rehabilitation package not specified.
Rodgers H., Atkinson C., Bond S. <i>et al</i>	1999	Stroke Education Program for patients and caregivers	Improvements in knowledge did not affect perceived health status.	Intervention not specific to therapeutic nursing.
Knapp P., Young J., House A. <i>et al</i>	2000	Non drug strategies for psycho-social recovery.	Literature review	Review of Medline, EMBASE and PsychLit. Secondary references checked. No new relevant studies identified.

Table 5.2 Table of related Studies

(Table 5.2 Continued)

Rodgers H., Atkinson C., Bond S. <i>et al</i>	1999	Stroke Education Program for patients and caregivers	Improvements in knowledge did not affect perceived health status.	Intervention not specific to therapeutic nursing.
Grant JS.	1999	Social problem solving	Intervention helpful for depression and problem- solving ability during intervention delivery.	Pilot study. Intervention aimed at carers only.
Dennis M., O'Rourke S., Slattery J. <i>et al</i>	1997	Family support worker intervention	Intervention may have precipitated passivity on the part of patients with concomitant negative outcomes.	Intervention not specific to therapeutic nursing.
Friedland JF. & McColl MA.	1992	Social support intervention	Intervention did not demonstrate any significant benefits	Intervention not specific to therapeutic nursing.

Table 5.2. Table of related studies

(Table 5.2 Continued)

Pasquarello M.	1990	Acute stroke program, incorporating patient teaching, support groups and telephone follow-up	Providing patient education and support as part of a total stroke program may improve compliance with medication and follow-up care.	Quasi-experimental. Not specific to therapeutic nursing.
Evans RL., Matlock AL., Bishop DS. <i>et al</i>	1988	Carer education, with or without problem solving skill development.	Counselling better than education alone at improving patient adjustment.	Three group RCT. Not specific to therapeutic nursing. Main focus was carers.

Table 5.2. Table of related studies

Author	Year	Intervention	Outcomes	Comments
Folden SL.	1993	Supportive-educative nursing intervention	Improvements in perceptions of self-care abilities	N=68. Quasi-experimental. Acute care based intervention.
Forster A. & Young J.	1996	Education and support (termed specialist nursing)	Small benefits for mildly disabled in terms of activities of living	N=240. Community based intervention. Weak theoretical framework.

Table 5.3. Table of included studies

Chapter 6

The Development of a Therapeutic Nursing Intervention

Introduction to the chapter

The earlier chapters of this thesis have constructed a framework of therapeutic nursing in stroke rehabilitation from a theoretical perspective, which has then been explored in a systematic review. Whilst justification for this framework can be established in the literature, there appear to be few studies that attempt to examine the benefits of this therapeutic nursing for patient health. Where intervention research has been identified that would appear to incorporate this therapeutic function, this is rarely articulated as such. Research of the effectiveness of therapeutic nursing in stroke rehabilitation therefore remains largely ignored in the literature.

The remainder of the thesis will therefore focus on the development, implementation and evaluation of aspects of the emerging framework. Specifically the framework will be used to construct a tangible, therapeutic nursing intervention, the potential of which to enhance the effectiveness of stroke services can be tested.

It is recognised that aspects of therapeutic nursing will be discernible in baseline clinical nursing practice in stroke rehabilitation. Indeed the observational studies of nursing role in stroke rehabilitation reported earlier in this thesis have been used in the construction of the framework. In addition, the development of the framework for therapeutic nursing recognises that therapeutic nursing interventions will be delivered alongside other aspects of the nursing role. It is impossible therefore to develop and implement a completely new therapeutic

nursing intervention, and compare the relative merits of therapeutic nursing versus another mode of nursing.

The development of the therapeutic nursing intervention in this study will build on current practice, using the emerging framework as a blueprint for action. This is a similar approach used in comparisons of the effectiveness of the organisation of stroke services. Aspects of multidisciplinary practice and specialist knowledge relating to stroke would be found in most general medical wards in the UK. Stroke units however build on these positive features, and consequently demonstrate considerable benefits for patients.

Whilst implementation and evaluation can, and should be cyclical, they are separated in this thesis for ease of explanation. The second part of the thesis focuses exclusively on the evaluation of the intervention. This chapter will therefore focus on the integration of material presented so far, to delineate and describe the therapeutic nursing intervention that will be carried forward to the second section of the thesis.

Therapeutic nursing

The key messages from research into the experience of recovery from stroke include the significant potential that the disease has to affect all aspects of an individual's world, challenging personal and social roles. The importance of relating to the biographical aspects of recovery during the total experience of disease has demonstrated the limitations of traditional models of stroke. An agenda for developing stroke services has been highlighted in this thesis,

attempting to reduce any disparity between the experience of disease and the professional interventions designed to promote recovery. Enhancing the therapeutic content of the nursing contribution to stroke patient care is proposed as one approach to reducing any disparity. The specific issues requiring consideration are prioritising the long-term psycho-social outcomes of stroke, and facilitating the development of coping and adaptation skills in patients and carers.

The elements of therapeutic nursing in stroke rehabilitation that have emerged in this thesis have focused on the nature of the relationship that develops between the patient, carer and nurse. There is an active use of that relationship on the part of the nurse to promote recovery. Here recovery includes adaptation to the consequences of stroke, with the emphasis on the development of an adapting and meaningful social world in which the patient can live. The mode of therapeutic nursing is then educative and supportive, and will include elements of counselling, teaching and other inter-personal skills.

The anticipated outcomes of therapeutic nursing are set in the medium to long-term and therefore challenge existing models of recovery from stroke. These have been demonstrated to reflect a two-stage model of recovery, acute and rehabilitation, and lack the temporal and biographical elements of psycho-social models of recovery such as the trajectory framework. Building the therapeutic content of nursing therefore requires the refocusing, or even reshaping of existing approaches to practice towards these elements of patient recovery.

Intervention development

The systematic review of therapeutic nursing in stroke rehabilitation demonstrates that both of the interventions studied have limitations. These relate principally to the restrictions placed on nurses to build therapeutic relationships with patients and carers by the organisation of care. The framework for therapeutic nursing developed in this thesis includes a priority being given to medium to long term outcomes of coping and adaptation to residual problems after stroke. This requires an ability by nurses working therapeutically to work across the artificial boundaries of health care, taking a long-term view to individual patterns of recovery. Restricting input to acute care (Folden, 1993) or community care (Forster & Young, 1996) is likely to reinforce the segmentation of recovery around organisational imperatives, rather than fostering the long-term view.

The development and implementation of the framework for therapeutic nursing in stroke rehabilitation was undertaken in one NHS trust in the north west of England. Here the baseline organisation of nursing care included the role of stroke nurse, whose principal responsibilities included

- provision of expert advice to nursing and other staff involved in stroke patient care, and
- planning of discharge arrangements for all stroke patients.

As with similar roles, the intervention of the stroke nurse was limited to the acute sector (Burton, 1999), and this role rarely had contact with patients after their discharge from hospital unless they were readmitted. Although the role will have incorporated the full range of technical, managerial and therapeutic care activities

defined earlier, the inability of this role to provide education and support to patients after discharge may be seen to limit its potential.

The promotion of the therapeutic content of this intervention was established through the provision of follow-up care after discharge from hospital. In this way, the relationship that developed between stroke nurse and patients, the cornerstone of therapeutic practice, could be maintained during and after discharge. The opportunities presented by the provision of follow-up care enabled the stroke nurse to focus on the medium to long-term nature of recovery from stroke. The revised role structure enabled a concentration on educative and supportive care, geared to the anticipated outcomes of therapeutic practice. Working with patients and their families in their individual social environment was postulated to provide the stroke nurse with considerable opportunity to explore new and meaningful ways of coping with the aftermath of stroke.

In summary, to expand the therapeutic content of the stroke nurse role, it was decided to

- provide the stroke nurse intervention during and after discharge from hospital,
- shift therapeutic relationships between stroke nurse and patient closer to the experience of recovery, and
- focus on education and supportive interventions in patient's own social environments.

In this way it was hoped that the intervention of the stroke nurse would promote coping and adaptation to the consequences of stroke.

The implications for clinical practice of the role expansion were negotiated with the host NHS trust that had participated in the development work. A multi-stakeholder steering group comprising members of the multidisciplinary team and service management participated in establishing the protocol for the expansion of the stroke nurse role. The protocol included arrangements for management and supervision of the role expansion, together with expected clinical activities, and are described in Table 6.1.

Professional development

The expansion of nursing practice does not make explicit a tangible end-point, where a clear knowledge and practice base can be defined (Atkins & Ersser, 2000). The framework for therapeutic practice in stroke rehabilitation provided a blueprint strategy for practice development. It did not however stipulate an explicit profile of micro-interventions that had to be performed competently. It was therefore clear that the stroke nurse required considerable support in addressing the implications of the framework development.

In this study, the framework for therapeutic nursing in stroke rehabilitation provided the boundaries and focus for the development of the stroke nurse role. After specification of tangible aspects of the role expansion, and in consultation with trust nursing management, an assessment of professional development needs was undertaken.

A bespoke package of professional development to support the expansion of the stroke nurse role was designed. The guiding principles that shaped the design of

the package were those proposed by the then professional governing authority, the United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC). These principles have been maintained by the superseding authority, the Nursing and Midwifery Council (NMC). The Scope of Professional Practice (UKCC, 1992) established that the prime responsibility for the expansion of nursing practice lay with the nurse. Whilst the strategy provided nurses with relative freedom to take on new roles and health care interventions, practitioners had to reassure themselves of the relevant knowledge and skill acquisition through their own, auditable professional development.

Organisational requirements for ensuring vicarious liability can be established in a number of different ways, including the establishment of boundaries for clinical practice, internal systems for quality assurance and clinical governance. Central to vicarious liability is the process of role development itself, and in particular the steps taken to ensure organisational preparation for safe clinical practice. Trust management were therefore included in all aspects of the role development and management to ensure that organisational requirements were met.

As part of the role expansion, documentation to be used in this study for clinical work was developed. This consisted of a proforma for clinical and demographic data, and essentially free-space to record all interactions between the stroke nurse and patients or their carers. A goal or pathway approach to documentation was specifically avoided, as neither were felt suitable to the nature of therapeutic nursing. Free text information presented the opportunity to record more in-depth information. This could be used to describe what actually happened to patients during receipt of the trial intervention on completion of the study.

Piloting

The constraints of funding imposed a rigid timescale for the implementation and evaluation of the stroke nurse role expansion. There was therefore only limited opportunity for piloting in a formal sense. It was therefore decided to implement the role expansion over a six week period, combining implementation with formative evaluation of role processes. The six patients who contributed to this aspect of the study were excluded from the formal, summative evaluation. Whilst this short run-in period enabled the most obvious clinical issues to be addressed, a decision was made to continue to provide professional support within clinical practice as the evaluation progressed.

The stroke nurse had been seconded to the research for a total of six weeks before the evaluation proper commenced. During this time regular debriefings were held with the stroke nurse to adapt role specifications and processes in response to the realities of clinical practice. There was a clear indication that, as with most aspects of health care, the more an intervention or therapy is performed, the more accomplished the professional performing it becomes. This is a potential weakness in the design of any evaluation, which can be dealt with in one of two ways:

- control through the use of explicit protocols specifying micro-intervention, or
- using the experience of intervention delivery as a source of data.

The pragmatic nature of the planned investigation of effectiveness of the expanded role required that the first option was rejected. A specific study was therefore planned, alongside the main evaluation, to capture data on this aspect of intervention delivery. In this way it was hoped that information on the context of

intervention delivery could be produced to support the generalisation of study findings.

Summary

In tangible terms, therapeutic nursing in stroke rehabilitation may be implemented through the explicit use of educative and supportive interventions to promote medium to long-term coping and adaptation to the consequences of stroke. Current norms of clinical nursing practice would appear to limit the ability of nursing to support recovery in this way, due to limited ability to work across health care boundaries and sectors. As a consequence, the features of alternative models of stroke recovery, and in particular the trajectory framework are difficult to implement.

A therapeutic nursing intervention has been described that builds on current clinical practice, which will directly support the implementation of a long-term view in patient management. The purpose of the intervention is to promote recovery from the perspective of the patient, and will include, amongst other things, adaptation to the physical, emotional and social consequences of the disease. The intervention has been implemented after appropriate professional development and continuing support. The second part of the thesis will investigate its impact in clinical practice.

Role expansion structure	Role expansion processes
<ul style="list-style-type: none">• Current practice as stroke nurse• Accredited post-registration courses in higher education environment• Current lines of managerial accountability• Professional supervision from a senior nurse in rehabilitation• Communication with research team to ascertain details of randomised patients for follow-up	<ul style="list-style-type: none">• Assessment prior to discharge focusing on physical, emotional and social dimensions of recovery• Home visit within two working days of discharge focusing on renegotiation of the home and social environment• Further home visits to support coping and adaptation• Provision of a contact telephone number for support and advice• Development of health promotion plans for patients and carers• Referral or re-referral to other agencies or professionals as indicated

Table 6.1. Clinical implications for the expansion of the existing stroke nurse role.

PART TWO

Chapter 7
Methodological Principles

Introduction to the chapter

This second part of the thesis is located within an emerging framework for health care evaluation which is underpinned by the major health sciences. Currently, largely due to a combination of socio-political factors and methodological advances, a focus on this approach to evaluation is a consistent feature of health care policy, and can for example, be witnessed in the promotion of evidence-based practice (National Health Service Executive, 1996). Here the focus of evaluation activity is on the production of knowledge of the effectiveness of health care interventions in the 'real world' of clinical practice, rather than knowledge per se. This chapter will consider the methodological underpinnings to evaluation in health care, and reconstruct a framework in which the evaluation of the therapeutic nursing intervention will be located. The chapter will also provide the theoretical basis required to underpin determination of the governance of the evaluation described in later chapters of the thesis.

Health care evaluation

There appears to be a persistent assumption that professionals in the public service sector are 'required to provide proof of their legitimacy and effectiveness in order to justify society's continued support' (Suchman, 1967 p2). It may be argued that this sentiment persists today, and is likely to persist for some time to come (Pollitt, 1988; Jordan, Dowsell, Harrison *et al*, 1998). The introduction of market principles into the organisation of health care in 1990 had profound implications for all health care professional groups, not least the importance of the challenge to evaluate and demonstrate the effectiveness of treatment, care or therapy. The

concept of effectiveness was considered as a measure of the degree to which a specific health care intervention, or set of interventions, was of proven benefit to a patient, and where the associated risk was at a level acceptable to patient and professional alike (Muir Gray, 2001). This concept is distinct from efficiency, which includes a notion of public utility in terms of wider economic consequences. This is an area of health care research that has only relatively recently received attention in the health research agenda (Drummond, 1994).

In the current context of health care, evaluation generally implies the critical assessment of the degree to which services, or component parts of that service, including treatment, fulfil stated goals (APHA, 1960; Suchman, 1967; Cochrane, 1972; St. Leger, Schnieden and Walsworth-Bell, 1992; Muir Gray, 2001). Specifically it will involve a number of steps, including:

- The formulation of objectives
- The identification of criteria to measure success
- The determination of the degree of success demonstrated by a given service or intervention, and
- Recommendations for action (APHA, 1960)

This combination of assessing value and recommending strategies for the future improvement of quality reinforces the dynamic and applied nature of evaluation activity, engaging with the ‘coal-face’ of public service activity. As such it is often employed in the ‘murky swamplands’ of the everyday experience and practice of professional and service user alike (Weiss, 1972; Schön, 1983). It is perhaps unsurprising therefore to find a plethora of approaches to evaluation and evaluation models in the health literature (Robson, 1993). The essential features of a viable evaluation do however include utility, propriety and technical adequacy.

Any evaluation is essentially a targeted activity, in that it will be designed to have some relevance by meeting the needs of a particular audience, often a commissioning body. This utility does however indicate the need for fairness in the design, execution and interpretation of the evaluation. For any given topic subject to evaluation, a range of differing, and sometimes conflicting interests or perspectives will be found amongst the individuals, groups or organisations that have a 'stake' in that topic. Maintaining a balance between those perspectives may be viewed as a pivotal feature of a high quality evaluation.

In practice ensuring that equal importance is attached to the perspectives of all stakeholders is difficult, with little guidance in the literature on this important ethical issue. For example, Hakim's generally admirable text on design in social research provides a somewhat naïve analysis of this point where the position of the evaluator is one of disinterest (Hakim, 1987 p146). Whilst this may be an optimistic stance to be able to take faced with the reality of research in the clinical arena, the propriety of an evaluation rests in the transparency and balance of decision-making in the early stages of study development. There should also be a recognition that balance may itself be subjective, and the implications for other stakeholders should be explored in the context of evaluation findings. Whilst objectivity may be a principle guiding choices in the evaluation methodology, subjectivity is a persistent feature in the setting of evaluation questions and outcomes.

Technical adequacy

This thesis draws an early and important distinction is drawn between formative evaluation and evaluation research, where formative evaluation involves a general process of assessment or the appraisal of value that is often situation specific. For many the concept of technical adequacy can be assessed by the proximity of a method for evaluation to the scientific method (Suchman, 1967). Indeed this point is reinforced by Robson (1993, p174) who states that 'evaluations are essentially indistinguishable from other research in terms of design, data collection techniques and methods of analysis'. The results of evaluation research should have generalisability to other health care settings and geographical locations. The relationship between evaluation research and other forms of research is however problematic in the UK, partly due to the current health research agenda and the definitions of what activities may be supported through the NHS R&D funding streams. This situation is changing however with the launch of the Service Delivery and Organisation research programme (NCCSDO, 2002), to focus on the evidence-base supporting the organisation, management and delivery of health care services.

NHS research strategies would appear to consider research and development as ends of a continuum: studies may be located on this continuum according to their pure, as in the case of research, or applied nature. Research focuses primarily on the generation of new knowledge (Department of Health, 1991), while the evaluation of interventions in the field, even if experimental methods are employed, tends towards the development end of the continuum. This distinction is highlighted when related evidence of the effectiveness of a given intervention

exists, as in the case of previous study in a different sector of the population. Changes in funding capacity and priorities may have focused attention on the pure end of research to the detriment of development, limiting the potential for replication studies, research on implementation strategies or evaluation research in general.

Reinforcing that the distinction between evaluation and evaluation research is one principally of process, Hakim's (1987) comparison between pure theoretical research and applied policy research can be used to explore the nature of this process: the research element in evaluation. The purpose of theoretical research is primarily to advance understanding within a given school of thought or research practice. The broad theoretical perspectives, language, questions and methodologies that underpin the development of knowledge are governed by the explicit and implicit understandings of members of that school of thought, often termed paradigm (Crotty, 1998). Policy research is however a 'broad church', incorporating a range of research approaches, addressing a range of issues relevant to the topic, issue or problem. In this respect, the constraints which govern theoretical research do not fit comfortably with the 'real world' environment of policy research. Policy research is often multidisciplinary in context or performance, and will address a range of perspectives on a topic, often through a programme of related studies. The focus of policy research is fundamentally different from theoretical research, where research questions tend to be defined from within the predominant paradigm, and its major theories. Policy research is focused on 'actionable' factors often defined from the field, and therefore requires the responsive use of a repertoire of methodologies.

Regardless of the interpretation placed on evaluation and research in the current political agenda, the principles of methodology remain the same. These principles are underpinned by the classical stance of the empiricism espoused by Francis Bacon and others, in which knowledge is gained by direct observation and measurement of phenomena in the natural world. Here methodology implies the testing of theories, which are derived from observation in an objective and rigorous way (Losee, 2001). In this case the epistemology of knowledge underpinning health care is one of objective, externalised laws or rules which can be generalised across patients, populations and health care settings. The role of the researcher in generating this knowledge is one of impartiality and distance from the experiment.

The translation of these principles into methodology is best demonstrated by the archetypal clinical trial, in which various strategies are used to ensure that two groups of participants are prognostically similar and therefore equally likely to benefit from an intervention (Chalmers, Smith, Blackburn *et al*, 1981). The clinical trial is variously described as some form of experiment on human subjects to determine the most appropriate treatment for a given medical condition. Whilst some definitions imply a simplicity in their design and execution (see Matthews, 2000 p1), it is clear that considerable care is required to ensure quality: poorly designed experiments on human subjects are likely to include considerable ethical risks. The emphasis on clinical trials in medicine is perhaps a realistic yardstick for the state of evaluation research in other health care professions, and particularly nursing, as will be discussed later in this chapter. Definitions should not however preclude or diminish their importance in building a broad evidence-base for health care.

Whilst modern clinical trials cover a number of phases, typically four, the first phase is generally concerned with the identification of types of treatment dosage and susceptibility. The phase two clinical trial is generally small-scale, and is concerned with the efficacy and safety of a given treatment. The phase three clinical trial is of particular relevance to this thesis, and involves a comparison between an experimental intervention and usual practice (Pocock, 1983). Given the wide variations in clinical practice at the level of locality, organisation and individual (Department of Health, 1996), it is essential that any comparison is made against practice based on the best available evidence of clinical effectiveness to prevent over-estimating the effectiveness of the new intervention.

The essential feature of phase three clinical trial is the comparison of the new treatment against a control group of similar patients. The quality of this comparison depends on the use of techniques to obtain a precise and true estimate of the treatment effect. Precision can be achieved by careful consideration of the size of the clinical trial, through adjusting acceptable levels of power, error and clinical significance (Pocock, 1983). Ensuring that a true and valid comparison between experimental and control treatments is achieved requires consideration of a number of factors including patient selection, concomitant treatment and equitable evaluation. Essentially there are two types of comparisons: the explanatory trial which provides evidence of efficacy in ideal conditions, and the pragmatic trial which studies clinical effectiveness (Schwartz and Lellouch, 1967). Thus the explanatory trial closely resembles the traditional phase two clinical trial.

The features of a pragmatic trial, particularly in relation to the evaluation of complex packages of health care, are discussed later in this chapter. Whilst the broad features of a pragmatic and explanatory trial are reasonably similar, the differences between these two approaches are summarised in Table 7.1

The key similarity between the two approaches is the presence of a control group, which acts as a benchmark for comparison between groups. To ensure that patients in the control and experimental groups do not differ at the start of a study, or are not pre-disposed to do so, the methods used to select those groups is of paramount importance. The experimental principle central to the management of this issue is randomisation, advocated as the gold-standard approach for ensuring a 'reliable assessment of treatment effectiveness' (Pocock, 1983 p51). This reliability is achieved as randomisation prevents the introduction of judgement or any other systematic method of introducing bias into a trial.

As with all experimental research however, a number of factors may challenge the validity of evaluation research, and consequently pose difficulties in attributing a detected treatment effect to the intervention of interest. Whilst these are described in a range of research methods texts (for example Robson, 1993), there are some issues that warrant particular attention when considering evaluation research in the field.

Changes in participants may however come from a variety of sources, including those external to the study, such as the environmental context of the study, or from the process of participation in the study itself. This will typically include interactions with trial staff, consenting to take part and contributing to the

collection of data. The management of most of these changes depends on the degree to which equivalence is achieved in the treatment of control and experimental groups, other than the intervention of interest, specified in the study protocol (Shepperd, Doll and Jenkinson, 1997).

Whilst the threats to internal validity of a clinical trial discussed so far have focused on the design and practical aspects of evaluation, there is the potential for 'human nature' to reduce scientific rigour. Those receiving treatments, administering treatments or evaluating those treatments may affect the eventual response unintentionally or otherwise (Pocock, 1983). The incorporation of either blinding or placebo treatments into a trial design has been advocated to minimise potential disruption in these cases. In the real world nature of evaluation research, both blinding and the use of placebos are notoriously difficult. In addition their uncritical use may limit the generalisability of study findings (Robson, 1993). The use of placebos and blinding are therefore generally restricted to explanatory trials. The recognition of the issue of 'human nature' as a potential threat to the validity of clinical trials also lies to some degree at the heart of criticisms of their underpinning philosophy.

Limitations of traditional approaches to health care evaluation

Traditional approaches to the generation of knowledge are underpinned by a scientific approach, grounded in the philosophies of positivism and empiricism, which stress the importance of engagement with an object of study in the development of knowledge. The ideal nature of this engagement in science is one of detached objectivity. These traditions are perhaps best witnessed in the medical

and health services arena, where their predominance is due to a range of social and historical factors. In simple terms, the dominant power base in health care has traditionally been medicine, which has for many years appeared to align itself with the methods of the natural sciences to develop its professional knowledge base.

A naïve analysis of evaluation will neglect the range of philosophical perspectives that underpin alternative approaches to evaluation, which focus on the relationship between research and evaluation. The process of evaluating is highly complex and subjective. The task of evaluation research therefore is to ‘control’ this subjectivity since it cannot be eliminated. This is done through the application of methods which should be underpinned by accepted standards in research methodology. Even through the rigorous use of these principles such as randomisation, evaluation research retains an intrinsic political theme. Goals imply that a given standard for the issue being evaluated exists, for example, best clinical practice as defined by the current evidence-base. In the definitions of evaluation cited in this thesis, a pivotal feature of any process of evaluation is the delineation of goals or aims of service. Additionally evaluation research requires the specification of the degree of success that is required. So for example evaluation research in therapy for people affected by stroke requires the consideration of two dimensions: the outcome to be evaluated, and the clinical significance of change in that outcome. These activities are, by their very nature, subjective and will be loaded with one or many stakeholder values.

These interpretations of evaluation research may run the risk of neglecting the consideration of unanticipated outcomes. This is of particular significance given

the usual time frames for funded evaluation studies: in stroke rehabilitation research for example, the follow-up of patients tends to be no longer than one year. Whilst in the real world it is unlikely to gain funding for longer projects, implementation of health technologies based on research with acceptable but limited time frames should include an evaluative element.

An emerging framework for health care evaluation

The growing importance attached to the results of evaluation research in informing decision-making in health care, coupled with awareness of the criticisms and limitations of traditional approaches to evaluation, has resulted in the emergence of new approaches to evaluation. The shift towards pragmatism in clinical trials perhaps best reflects the growing sense of realism in clinical research advocated by the post-positivist school of thought. Here there is a reconsideration of the historical stance of positivism which focused on the 'truthfulness' of causal relationships in the natural world, in favour of the cumulative probabilistic growth of knowledge (Ford-Gilboe, Campbell and Berman, 1995). The choice of research methods in this case are dependent on both the primary objectives and context of a given study. There are three issues which perhaps best reflect this development: limiting reductionism in evaluation research, the management of stakeholder perspectives, and the incorporation of intention to treat in data analysis, all of which are gaining credence in modern health care research and development strategies.

The complexities, and dangers, of reducing health care to discrete component parts which may then be tested has already been highlighted. Rather than rejecting

traditional scientific principles in evaluation research, there is an emerging recognition that traditional principles may be applied to the evaluation of 'whole' aspects of health care. Purists would argue for the removal of any potential for the effects other than those of a discrete intervention, for example through the use of a placebo in a drug trial. It is possible however, where understanding of the active ingredient is at a theoretical level, to consider the intervention as a whole and incorporate other strategies to explore and identify its effective component parts.

The Medical Research Council (MRC) in its guidance refers to the concept of a 'complex' health care intervention which may include a number of 'active ingredients' (MRC, 2000). Here the purpose of evaluation is to identify those ingredients that are effective so that they can be applied generally. The notion of complexity is highlighted by the consideration of the targets of complex interventions, which may be aimed at either professional or patient, and at an individual, service or population level. Although published after work on this thesis began, the MRC framework presents a flexible strategy for health care evaluation which, to some degree resembles the development work underpinning both the study intervention and the evaluation strategy. It therefore seems sensible to relate the framework to aspects of this study.

The framework consists of five stages, which are analogous to the more common phases of a clinical trial (Table 7.2). The *Theory Phase* represents the choice of a theoretical stance to underpin both the description of the intervention, and its anticipated outcomes. It is advocated that a theoretical stance will provide the basis for mapping the inter-relationships and anticipated outcomes of component parts of the intervention. This *Modelling Phase* may include reference to those

who either deliver or receive the intervention. In essence both phases are inductive in that their real purpose is to provide some theoretical basis from which to build the evaluation strategy, and to provide a benchmark for scientific discussion about the findings of evaluation.

A traditional phase two trial is essentially a small scale investigation which usually will focus on the general performance of an intervention, including the identification of potentially adverse effects. Applying this focus to a complex intervention would suggest that this phase is concerned with the development of a robust evaluation strategy, identifying active components within the intervention, and constructing a suitable protocol. In many respect this *exploratory trial* phase may be seen as a pilot investigation, where the focus is not on the clinical effectiveness of the complex intervention, rather the viability of the evaluation strategy.

The MRC framework identifies the *definitive randomised controlled trial* phase as the central step in the evaluation of a complex intervention, highlighting the importance of standard indicators of trial validity as benchmarks for quality. Similarly to traditional phase four drug trials which are not deemed to be part of the research enterprise (Pocock, 1983), the *long-term implementation* advocated in the guidance suggests that observational studies are employed to identify contextual issues that may be important in shaping the effectiveness of the complex intervention.

This thesis takes the view that whilst this approach to the evaluation of ‘complex’ interventions has significant potential to assist in the identification of effective

health care, its use needs careful *a priori* consideration. From a philosophical perspective, science has relied heavily on the ability to 'see' the natural world in which it operates. Our ability to see further has facilitated the growth of disciplines concerned with entities and matter of a microscopic nature. There is a need therefore to recognise that complexity may mean a methodological inability to identify and consider those component parts. For example, developments in psychometrics have in recent years facilitated a closer and more credible attention to issues such as quality of life.

Whilst there are obvious practical benefits, there are also dangers in the wholesale move to pragmatism in health care research, not least the uncritical acceptance of structures and processes that underpin healthcare decision-making for the expediency of research endeavour. As with any approach to research, it is the evaluation question that must lead the development of methodology and methods, rather than uncritical adoption of the latest methodological advance.

Whilst not exclusive, there are two further features of an evaluation study that warrant particular attention for this thesis. Both are consistent with the pragmatism evident in emerging frameworks, and are used in the construction of this thesis. They are the triangulation of stakeholder perspectives and the adoption of an intention-to-treat principle in the management of an evaluation study.

The importance of ensuring fair representation of the interests of different stakeholder groups in the design and execution of a piece of evaluation research is paramount. Little advice on how to do this in research practice can be found, and what literature is available usually refers to the assessment of health needs at

community level. Here for example, the identification of different stakeholder perspectives on community health needs using rapid appraisal methodology has been advocated (Ong, 1993). Whilst recognising the existence of alternative priorities held for example by patients, professionals and managers, clear proposals for the integration of these perspectives is absent. One feature of evaluation research that may have potential to manage the interests of different stakeholders is triangulation.

Broadly speaking triangulation refers to the combination of a range of research features, and is defined by the level of those features which include data, methodological, theoretical and investigator (Denzin, 1978; Duffy, 1987; Dootson, 1995), and are described in Table 7.3. All are employed to some degree in the construction of this thesis.

Investigator triangulation, which enables continuous peer review of research processes, may by default encourage the scrutiny of assumptions underpinning an evaluation research study. Collecting data from alternative sources, for example on patient and professional perceptions of what constitutes a good outcome from stroke rehabilitation services, may also be useful in identifying discrepancies and areas of agreement. Managing those differences remains problematic. This issue also applies to theoretical and methodological triangulation which are in essence related solely to the generation and analysis of data for different stakeholder groups rather than integration across stakeholder groups.

Whereas methodological triangulation has tended to be interpreted at the level of method, the true combination of methodologies, as for example in the case of

programmatic research, presents some opportunity for the integration of stakeholder perspectives. Here individual research studies do not attempt to grapple themselves with those different agendas. Each will have a specific research aim which ideally should be addressed to one particular perspective. Studies can then be integrated thematically, with findings rather than data used to contextualise and offer potential explanations for patterns across studies. There are three studies in this thesis which are combined methodologically in this thesis

- a randomised controlled trial which essentially focuses on professional indicators of clinical effectiveness
- a study of intervention acceptability that focuses on patient perceptions, and
- a study of intervention performance which addresses the wider stakeholder agendas within the practice arena

These studies are described in more detail in the following chapter. This description of methodological triangulation sits comfortably with the prevailing philosophy underpinning post-positivism, and the focus on cumulative approaches to the generation of knowledge.

The adoption of intention to treat as a strategy for the analysis of data from clinical trials is also testament to a shift towards pragmatism in research, and strongly recommended in quality benchmarks for clinical trials (Moher, Schulz, Altman *et al.* 2001). In simple terms, the strategy requires the comparison of patients in a clinical trial according to the groups to which they are originally assigned at randomisation, even where protocol violations or other factors might suggest they should be excluded. This stance reflects the multitude of issues that can disrupt a trial including patient ineligibility, withdrawals, cross-over between groups, mortality, clinical errors with the administration of the trial intervention

and the like. It is postulated that including this group of patients in analysis reduces the possibility of overestimating any clinical effectiveness (Hollis and Campbell, 1999; Matthews, 2000).

A number of similar recommendations for using intention to treat in research practice can be found in the literature (for example, Hollis and Campbell, 1999), including

- attempting to minimise missing responses on the primary outcome
- if possible, following up all patients who withdraw from treatment
- investigating the potential effect of missing responses

Although obtaining continued consent for assessment from those who withdraw from treatment may be difficult, these ideas appear to reflect the possibilities for ensuring the maximum amount of information is available to those reporting a clinical trial. What is also essential however is to ensure the careful collection of data relating to patient end-points, with consideration given to the theoretical classification of potential outcomes. Whilst limiting the amount of time between randomisation and intervention administration is useful to enhance general trial validity, it may also help to limit withdrawal prior to randomisation, and so reduce this group in any intention to treat analysis.

Whilst this strategy for data analysis reflects the real world nature of clinical research and practice, inevitably it raises questions about the management of missing data. Little consensus can be found in the literature that addresses this issue, however the incorporation of sensitivity analyses has been advocated (Shih, 2002). Typically these should include undertaking between group comparisons including all available data. The legitimacy of these findings should then be

confirmed through repeating statistical analyses, through the substitution of scores where data is missing. The substitution of the last recorded data from an earlier measurement point is one technique that may be used, however this is likely to produce a conservative estimate of treatment effect, particularly where recovery may be gradual and long term. A second substitution technique includes the allocation of a population measure of central tendency. Again this may provide a spurious estimate of the treatment effect, unless patients with missing data are unlikely to be 'average'. Where data is missing due to patient death, the substitution of extreme values has also been advocated, for example scoring zero on a quality of life assessment tool. This technique does however have the capacity to skew a distribution, and is less useful when patient death is unlikely to be due to a trial intervention. As this analysis demonstrates, the management of missing data in pragmatic trials is an evolving science.

Emerging frameworks appear to have some potential in addressing some of the inherent criticisms of traditional approaches to evaluation research, particularly in capturing the real world nature of the context of evaluation research and the difficulties in managing competing stakeholder perspectives. Their application to stroke rehabilitation has appeared to be encouraging.

Evaluation in stroke rehabilitation research

In the UK, work to scope the stroke rehabilitation literature has adopted a more narrative approach to synthesis, resulting in the production of a bulletin focusing primarily on the location of stroke rehabilitation and the contributions of different professional groups (University of Leeds, 1992). The bulletin recognises the

inadequacy of the research base in this area, and makes some recommendations for the design and conduct of clinical trials in stroke rehabilitation, including:

- the importance of using suitable control groups
- the use of sufficient power to reduce the potential for type II errors and to allow sub-group analysis depending on the type of stroke
- the use of batteries of outcome measures including disease-specific and quality of life measures, and
- consideration of the economics of interventions in stroke rehabilitation.

One major weakness in this report however is the absence of nursing in the report. This is surprising given the high volume of contact that those affected by stroke have with nurses during an in-patient episode. Recent NHS strategy documents continue to highlight that nearly 80% of all care and treatment is provided by nurses (Department of Health, 2001).

The emergence in recent years of the systematic review as a research methodology in its own right has had positive outcomes in the field of stroke rehabilitation research. Systematic reviews of alternative approaches to the organisation of stroke services have been encouraging (Ottenbacher and Jannell, 1993; Stroke Unit Trialists' Collaboration, 2002), and are at the heart of many service development initiatives. Inspection indicates that the trials that are incorporated in the review can easily be viewed as complex packages of intervention. Despite clear evidence of the effectiveness of stroke unit care as a whole, little is known of what constitutes the active components of what is essentially a broad strategy for patient management (Wade, 2001). Despite this apparent 'weakness' from the purist sense, the systematic review now underpins

much of the content of the National Clinical Guidelines for Stroke (Intercollegiate Working Party for Stroke, 2000).

Progress with evaluation research in nursing

Whilst nursing has consistently articulated the importance of evaluation of the professional repertoire, progress can best be said to be limited. Cullum for example, a key exponent of the evidence-based nursing agenda, demonstrated few rigorous evaluations in a comprehensive review of randomised controlled trials of nursing interventions (Cullum, 1997). It is postulated that paradigmatic resistance to clinical trials in nursing has hampered progress in this area (Closs and Cheater, 1999). Indeed growing features of the nursing literature are studies which allude to either phenomenological or ethnographic underpinnings (Johnson 1999), and critiques of the application of technical, rational scientific principles to nursing issues such as anxiety, stress, social adjustment and depression. It may be argued however that the focus on theoretical and consequently methodological aspects of evaluation in the nursing literature has been to the detriment of tangible evaluative research of nursing interventions.

The history of evaluation in nursing was plotted by Tina Koch (1994) using a framework derived from Guba and Lincoln (1989). This framework describes a shift from the simple measurement of attributes, the archetypical nursing observations, to an assessment of attainment against pre-determined objectives, characterised for example by the nursing process. The move to judgement-orientated evaluation involving recourse to peer professional assessments of achievement is then cited as the precursor to their notion of fourth-generation

evaluation. This approach to evaluation in nursing is located in the divergent variety of concerns and issues that can be raised by stakeholders through dialogue in the field. The task of the investigator in this type of evaluation activity then is to construct a synthesis of stakeholder perspectives, which may include service development as either process or outcome of the evaluation activity. Its philosophical basis is similar therefore to other post-modern humanistic methods of enquiry such as action research (Hart and Bond, 1995).

The dangers in this approach to the criticism of evaluation activity in nursing lie however in the presentation of these issues as a simplistic linear model with a clear temporal dimension. Doing so suggests that a clear progression through different approaches to evaluation can be identified in the professional literature. Additionally there is the implicit assumption that an agreement exists on the primacy of 'newer' approaches to evaluation over more goal-based measurement approaches to evaluation. Recent review and theoretical papers such as Johnson (1999) demonstrate neither of these assertions can be held up to scrutiny. What is evident in the literature is a discourse that focuses on the purpose and context of an evaluation as being instrumental in influencing decisions about its design.

This analysis would indicate that the agenda for the evaluation of nursing interventions in stroke rehabilitation is doubly difficult, with little evidence of benchmarks for evaluation quality in the scientific literature. There are, however some key lessons which have been useful in underpinning the development, execution and analysis of this study.

Application of principles to the thesis

Whilst the working methods for this study are described in detail in the following chapter, it is worth summarising how the methodological principles discussed in this chapter have specifically influenced study design.

The theoretical work underpinning the development of the trial intervention clearly highlights the potential disparity between patient and professional interpretations of recovery. It is therefore self evident that determining goals for an evaluation of the study intervention would be difficult, with potentially different patient and professional priorities for benefit. A programmatic approach to the development of an evaluation of the intervention has therefore been taken, with separate studies addressing the priorities and concerns of both stakeholder groups. These studies will be triangulated at a thematic level to provide an integrative assessment of the value of the intervention.

Establishing continued nursing case management after discharge from hospital must be viewed at best as a complex intervention. A requirement of the intervention to be flexible and responsive to individual patient needs further reinforces the complex and potentially variable nature of the study intervention. The hallmarks for a quality investigation of a health care intervention remain consistent with those of the archetypal randomised controlled trial, and have provided a direction for the design of a responsive but credible assessment of the value of the study intervention.

There is a recognition that this study will not provide definitive identification of the benefits or otherwise of providing therapeutic nursing interventions through continuing nursing case management to patients with stroke after discharge from hospital. The complex nature of the intervention, and the pragmatic influence of its evaluation will mean that, in post-positivist style, an approximation of effectiveness will be sought. A style of clear and open reporting to enable understanding of the context in which this study sits, and the identification of salient features to aid implementation with concomitant evaluation will be attempted.

Explanatory	Pragmatic
Intervention studied in laboratory conditions	Intervention studied in clinical practice
Focus on efficacy	Focus on effectiveness
Clearly defined rigid application of intervention	Some degree of flexibility in application, often due to contextual factors
Tight inclusion and exclusion criteria	A degree of heterogeneity in study population characteristics similar to a 'real' population
Discrete outcomes of interest	Broad outcomes of interest

Table 7.1. Key differences between a pragmatic and explanatory clinical trial.

Trial phase	Framework phase	Description of framework phase
Pre-clinical	Theory	Use of literature to identify hypothesis and to predict major confounders
1	Modelling	Identification of mechanisms and inter-relationships underlying the intervention
2	Exploratory trial	Identification of constant and variable components of an intervention, an appropriate alternative, and a feasible protocol for comparison
3	Definitive RCT	Comparison of a defined intervention using a defensible protocol
4	Long-term implementation	Replication of results in uncontrolled settings over a period of time

Table 7.2. MRC framework for the development and evaluation of complex interventions.¹

¹ Adapted from Medical Research Council (2000)

Triangulation	Description
Data	The use of alternative sources of data to verify or contrast perceptions
Methodological	The use of alternative methods of data collection
Theoretical	The incorporation of a number of theoretical perspectives in the delineation of assessment domains
Investigator	The use of more than one investigator in a study

Table 7.3. A description of alternative approaches to triangulation

Chapter 8

Working Methods

Introduction to the chapter

This chapter will detail an evaluation research study designed to test the effectiveness of a therapeutic nursing intervention. Part One of this thesis constructed a theoretical framework for therapeutic nursing practice in stroke rehabilitation. The importance of this framework in providing direction for the advancement of clinical nursing practice was highlighted.

Implementation of the framework in clinical practice has focused on the role of the stroke nurse. This role, consistent with the development of nursing practice across the north-west of England (Burton, 1999), was expanded to provide therapeutic nursing interventions through continuing nursing case management after discharge from hospital. Interactions between the stroke nurse and those directly affected by stroke were educative and supportive in nature, focusing on the development of coping skills and the development of a meaningful healthy lifestyle. The first chapter of this second part of the thesis has set out the broad methodological principles that will be used to underpin the evaluation research study. This chapter will report the implementation of working methods.

The CONSORT statement

The increasing importance of the role of clinical trial results in providing signposts for health care practice has been problematic, where poor quality reporting has hidden deficiencies in trial design. The assessment of internal validity, and in particular bias due to ineffective randomisation, is a critical aspect of research appraisal (Moher, Schulz, Altman *et al.* 2001). The emergence of

evidence-based practice as a central feature of health care development has to some degree precipitated a review of the quality and credibility of traditional approaches to reporting clinical research. Increased emphasis on appraisal in pre and post qualifying programmes has increased awareness of what information is required in a trial report. This, coupled with a recognition of the potential consequences and prevalence of scientific fraud (DeMets, 1997), has renewed interest in the quality of the dissemination of research findings, and in particular journal reporting of clinical trials.

The CONSORT (Consolidated Standards of Reporting Trials) statement has in recent years set a benchmark for the quality of clinical trial reporting, and will be used to underpin the presentation of material in this chapter. The first CONSORT statement was published in the Journal of the American Medical Association in 1996 (Begg, Cho, Eastwood *et al.* 1996) with a recent revision published in 2001 (Moher, Schulz, Altman *et al.* 2001). The general process of statement development is iterative, with recourse to international consensus. The most recent guidelines propose 22 items that require consideration in a trial report, and recommend the use of a flow-chart to demonstrate patterns of subject recruitment, withdrawal and completion. These have been summarised and are reproduced in Table 8.1.

The key differences between the original and current statement focus on the consideration of trial funding and ethical considerations: the current statement suggests that explicit description of these issues is not formally required. The CONSORT group do however recognise the importance of these aspects of research design, which after all attest to governance and integrity of a study, and

recommend their inclusion if it is felt appropriate. Each section of this and the following chapter will be directly underpinned by the most recent CONSORT statement. Whilst attempting to conform to the CONSORT statement, the academic purpose of this thesis will require that attention is paid to the full range of issues that are relevant in the design of an evaluation research study, and where relevant their theoretical underpinnings. This chapter will therefore include additional material on the triangulation of methods, the process of assessment and assessment tools, sampling and statistical methods. Where necessary, additional information will also be provided to aid assessment of governance and generalisability.

Study design

This study employed a pragmatic randomised controlled trial design, comprising two parallel trial arms. The experimental evaluation was augmented by three associated studies. These focused on

- intervention acceptability
- intervention intensity
- intervention implementation

Funding

The study was provided with funding (£42,269) by the National Health Service Executive (North West) reactive funding scheme. The purpose of this scheme was to respond to the research and development needs of health care within the north-west, whilst providing some research capability building. The study was funded as

a pilot study. Funding does not imply that the National Health Service Executive (North West) endorse the content of this thesis, and the views expressed herein are solely those of the author.

Specifically funds were made available to support the following:

- independent randomisation service
- copyright costs associated with assessment tool use
- secondment of staff from practice to participate in the research
- travel costs

The secondment of staff from clinical practice was formalised in a memorandum of co-operation specifying the terms for staff release and the repayment of staff costs.

Ethical review

The study was approved by two local research ethics committees. Whilst the two district hospitals who contributed patients to the study were managed by one NHS Trust, the arrangements for the management of research and development activity remained separate. Copies of both ethical approval letters are enclosed in Appendix 1.

Initial discussions with the ethics committees demonstrated the importance of informed consent, with the imposition of a requirement to obtain consent prior to each assessment rather than solely on entry to the trial. One committee required the review of the format of the patient information sheet in line with hospital requirements. This was however conditional on whether a review of the consent

documentation was undertaken during the study. As no problems with recruitment were identified during the lifetime of the trial, the patient information sheet remained unchanged at both hospitals.

One ethical issue was however raised in the early stages of the trial through the study steering group. This related to an item on one of the assessment tools, the Beck Depression Inventory, which concerned suicidal ideation. Identifying clear suicidal intent, and failing to undertake appropriate intervention could be construed as failing to meet acceptable standards of professional practice. Advice was taken from the Community Psychiatric Nurse who covered both hospital sites, and a protocol drawn up for action if suicidal intent was demonstrated by any study participant.

Study setting

One of the key issues which may affect the generalisability of trial findings is the location of the study. Historically much clinical research has been undertaken in tertiary referral centres, attached to academic University departments (Drummond and Davies, 1991). The populations served by these departments do tend to be atypical in a number of ways, including disease type, progression and severity. Whilst there are obvious benefits from concentrating research expertise in a critical mass, this feature will affect the generalisability of research findings to the wider population. As a consequence the frank reporting of study site characteristics, including available services, will facilitate the assessment of structural issues which may affect the wider application of findings.

In this study the setting was a merged National Health Service trust in the north west of England. The trust incorporated two district general hospitals in different locations. One hospital, hospital A, was located in a seaside town whilst the other, hospital B, served a market town some 12 miles inland. For stroke patients at hospital B, there was an accident and emergency department, four medical wards and a generic rehabilitation unit. At hospital A however an accident and emergency department served 6 medical wards. The rehabilitation unit, again generic, was located in a smaller hospital, closer to the town centre. This hospital, hospital C, only had an out-patients department and two other, long-stay wards. No stroke patients were admitted directly to hospital C in the trial.

Hospital A was served by one multidisciplinary team, comprising consultant, physiotherapist, occupational therapist, speech and language therapist and nursing staff. A separate team with similar membership was attached to hospitals B and C, with the team covering both hospital sites. Follow-up and community services were again provided separately by both sites.

Patients were admitted to a variety of clinical settings: not all patients experienced a stay on a rehabilitation unit. This profile of services and resources available for stroke patients was consistent with national norms (Stroke Association, 1999).

During the very early stages of the development of this study, the hospitals in the two towns were managed by separate NHS trusts. For this reason the study was intended only for hospital A. The merger however facilitated the expansion of the study, and an increase in the available study population. Structural differences between the hospitals, the organisation of services and the differences in staffing

could have affected the validity of the trial. For this reason, the admitting hospital, A or B, was chosen as a stratification factor in randomisation.

Whilst the stroke nurse worked across both hospital sites, other staff remained attached to one hospital. The merger did precipitate a review of stroke services undertaken by an external consultancy, to which this study contributed. No significant changes were however made to the organisation and delivery of stroke services during the lifetime of this trial.

Study population

All patients admitted to hospitals A or B with a diagnosis of stroke were approached for admission to the study prior to discharge. The entry criteria were an absence of pre-stroke clinical depression, multi-infarct dementia, concurrent medical condition with a poor prognosis, or previous alcohol or drug dependence. Whilst it was hoped to maximise the generalisability of the patient population in the trial, it was felt that these factors had significant potential to threaten the validity of the trial. These criteria are consistent with those of related studies identified in the systematic review in part one of the thesis.

Recruitment

All stroke patients admitted to either hospital A or B were reported to the stroke nurse as a matter of course, and were thus readily identifiable. Regular checks were also made on all relevant wards at all hospitals to ensure that no potential participants were lost, for example when the stroke nurse was on leave or absent.

Before a patient was approached for recruitment, a check of their clinical condition was made with the nurse in charge of that patient's care. Patients were approached for recruitment as soon as clinical staff felt that their condition had stabilised. As a consequence patients were recruited from all relevant ward areas, including medical admissions wards, general medical wards and the rehabilitation units. Medical notes were screened for the presence of exclusion criteria.

Patients were then provided with a study information sheet (Appendix 2) which was explained to them. If they were happy to proceed, then consent was taken at that time (Appendix 3). If however they wished to discuss involvement with family or carers, then an appointment was made to return. Where patients were unable to consent, then an appointment to obtain consent from the next of kin was made. All recruitment procedures were approved by the local research ethics committees.

Once consent had been obtained, a trial registration form was completed immediately (Appendix 4). This form collected demographic data, baseline data and other information required for randomisation.

Experimental group

The study intervention was underpinned by the framework for therapeutic nursing practice in stroke rehabilitation, the central features of which are:

- a focus on the concerns of those directly affected by stroke,
- the use of the therapeutic relationship between nurse and patient as a medium for education and support

The anticipated outcomes of therapeutic nursing practice include coping and adaptation to the full range of physical, social and emotional stroke sequelae.

The framework was implemented through continued follow-up of stroke patients by the stroke nurse after discharge from hospital. This nurse continued to see randomised patients either in the out-patients department, day hospital or community, and undertook the following:

- the development and maintenance of an individual plan of rehabilitation, including the identification and negotiation of individual outcomes or goals, risks and associated interventions with patients and carers,
- the promotion of health and coping skills, and risk management strategies with patients and carers, and
- emotional support for patients and carers.

A follow-up visit within two working days of discharge was the minimum requirement for the intervention. The purpose of the visit was to undertake an holistic assessment of the potential for recovery in the patient's place of discharge to guide the planning of future follow-up and assessment. This visit included the provision of a telephone contact number where patients or carers could contact the stroke nurse. When away from the office this number was attached to an answering machine where messages could be left. Patients were advised not to use this number in an emergency. At this visit the stroke nurse specifically reviewed the following issues:

- physical functioning using activities of living
- patient and carer knowledge of the consequences and implications of stroke
- patient and carer abilities to cope emotionally with the aftermath of stroke

- the potential of the home environment to support recovery
- a review of medication for adherence, appropriateness and effectiveness
- transfer of care arrangements, and
- health promotion including patient and carer education, stroke prevention and the use of resources to support recovery.

Based on the findings of this review an individual rehabilitation plan was established to guide further intervention and follow-up. In accordance with the purpose and theoretical underpinnings of role expansion, subsequent input by the stroke nurse was flexible, determined by the stroke nurse in consultation with the patient and carer. The principles of professional development governing the expansion of nursing practice to include this intervention have been outlined in Chapter 6. There was however a programme of training to support these aspects of the intervention. The training plan to support these interventions is summarised in Appendix 5. It should be noted however that the training and development plan specifically reflected the existing knowledge and expertise of the individual performing the trial intervention and may need to be varied in other settings.

All contact between the stroke nurse and patients was recorded on documentation specially designed for the trial. This documentation was commenced on discharge from hospital, and relevant material was transferred from hospital notes by the stroke nurse. This documentation was used in an associated study of the sub-types and intensity of trial intervention.

Control group

The control group comprised patients who received usual care and follow-up on discharge from the rehabilitation unit. This included inpatient case management by the stroke nurse. Usual care was structured on a multidisciplinary model, and consequently conformed to principles of 'best-practice' as determined by the current evidence-base. At the time of the trial, the co-ordination of care was organised through multidisciplinary case conferences chaired by the consultant. Various referrals and discharge arrangements were organised through this forum. Nursing input in case conferences was provided by the nurse responsible for that patient's care.

Patients in the control group did not receive a home visit or any further intervention from the stroke nurse. Both control and experimental group patients did however receive usual follow-up services, including liaison with the patient's general practitioner, out-patient follow-up, and access to multi-professional rehabilitation services provided in either a day-hospital or the community.

Objectives and hypotheses

The major study objective was to determine the clinical effectiveness of providing continued stroke nurse follow-up after discharge from hospital.

The study addressed the following null hypotheses:

- that there will be no difference in the perceived general health of those participants who received continued stroke nurse follow-up after discharge from hospital and those participant who received usual care
- that there will be no difference in the physical dependency of those participants who received continued stroke nurse follow-up after discharge from hospital and those participants who received usual care
- that there will be no difference in depression in those participants who received continued stroke nurse follow-up after discharge from hospital and those participants who received usual care
- that there will be no difference in the performance of activities of daily living by those participants who received continued stroke nurse follow-up after discharge from hospital and those participants who received usual care
- that there will be no difference in strain reported by the carers of those participants who received continued stroke nurse follow-up after discharge from hospital and those carers of participants who received usual care

In a traditional approach to research the null hypotheses will tend to guide decisions about trial design. In this study however, whilst the major study objective was consistent throughout, the null hypotheses were dependent on the selection of domains for assessment, and the availability of credible assessment tools. The decisions taken to finalise these choices were complex, dependent on theory, research and practice issues, and are discussed later in the chapter. The null hypotheses listed above were specified late in the development of the trial design.

Assessment

The importance of including the assessment of both clinical and economic factors in a clinical trial has been highlighted in the previous chapter. Whilst it has been shown that there is little to guide the selection of economic factors in the stroke rehabilitation literature, consideration of the following issues were included in this study:

- length of stay
- general profile of follow-up services
- intervention costs

The study intervention was planned as an additional element to an existing profile of services. An analysis of the profile of services received by patients in each of the groups was therefore undertaken to assess the equivalence of the cost of services across both experimental and control groups. Equivalence was considered by two proxy indicators, the length of inpatient stay, and the distribution of follow-up services. Consequently a decision was taken to focus detailed study on the specific costs of the trial intervention, rather than stroke services in general.

There are fundamental differences in the processes of measurement in research, which implies the existence of some form of standard unit, and assessment, a process of evaluation where such standardisation does not exist (Wade, 1992). In stroke rehabilitation, where the range of issues that could be considered potentially useful for quantification is extensive, there is little opportunity for standardisation at all but the simplest level, for example age and length of stay. It is unsurprising therefore to find a plethora of tools in the literature that purport to

quantify aspects of recovery. For this reason, and for the purposes of this thesis, the more appropriate concept of assessment will be used.

The selection of assessment tools to use in stroke rehabilitation evaluation research may be guided by a number of different factors, including

- the research agenda
- relevant theoretical frameworks, and
- the performance of individual assessment tools.

The first factor may be considered in two ways: the development of specific evaluation questions through management of stakeholder group interests, or the issues prevalent in the research agenda in a given field. Whilst the management of stakeholder interests was discussed in detail in the last chapter, it is worth reiterating that the selection of assessment tools needs to be undertaken in a transparent fashion, with a view to ensuring breadth and relevance.

A frequent feature of debate in the stroke rehabilitation research literature identifies the importance of psycho-social outcomes (Seale and Davies, 1987; Evans and Bishop, 1990; Wade, 1992). Whilst in some respects pathological changes and disability may be easier to assess, there is a growing recognition that the wider consequences of disease, and in particular handicap have consistently been neglected in research (Wade, 1992). This is encapsulated by the stroke rehabilitation *Effective Health Care Bulletin* (University of Leeds, 1992 p9) which state that ‘rehabilitation trials should consider a profile of outcome measures which address the various dimensions of impairment, disability and handicap that can follow a stroke. The development and use of patient and carer-centred

outcomes should be encouraged, such as measures of well-being, quality of life and satisfaction’.

Whilst there are clear messages in the literature to increase the breadth of assessment tools in stroke rehabilitation research, the implementation of research use strategies in UK health care, and most notably the growth of systematic reviews, will also influence the choice of assessment tools. Some consistency is required in the use of assessment tools across clinical trials to enable meta-analysis across studies of similar interventions (University of Leeds, 1992; NHS CRD, 1996). This was a key factor in the decisions about assessment tools that were reached in the development of the protocol for this study. The profile of assessment tools in studies identified in the systematic review is given in Table 8.2.

Regardless of the issues pertinent to the prevailing stroke rehabilitation research agenda, the selection of assessment tools must also be justified by reference to relevant theoretical frameworks. In this way the pitfalls in previous research, or the overindulgence of any one stakeholder group in assessment can be minimised.

There are two theoretical frameworks that have guided the choice of assessment tools in this study. Firstly, Donabedian’s framework for the consideration of health care quality focuses attention on three constructs: the structure and organisation of services, the process of health care intervention itself, and the outcomes achieved by care and therapy (Donabedian, 1966). The assessment domains identified so far can all be classified as outcomes.

Using the framework to guide the choice of assessment tools has the potential to increase the validity of a study, principally in the degree of confidence that may be used in explaining detected treatment effects. These effects will be most important clinically where they are located at the level of outcome for the patient, that is a change in patient status such as mobility or perceived general health. Where this change in outcome fails to be matched by a change in factors attributed to the process construct, this should suggest that a degree of scepticism in the validity of supposed treatment effects is required. This is particularly the case in this type of evaluation research where the intervention of interest is complex in nature. It is not unreasonable to expect this study intervention to have some impact on the general delivery of services, care and therapy if it is to facilitate some change in patient outcome. It is for this reason that this study will include a range of assessment tools that consider identified factors at the level of both the process and outcome construct (Table 8.3).

As the trial intervention is an additional element to usual care and follow-up, a decision was made to focus on the brief assessment of services to ensure comparability across both treatment arms. A description of the collection of more detailed data on trial intervention intensity is given later in this chapter. It is not unreasonable however to expect the provision of community services to differ between the two arms. The stroke nurse may identify additional problems after discharge and refer to other professionals for additional or alternative services. This situation may make the attribution of causative links between trial intervention and patient outcome more difficult in one respect: the potential beneficial effects of multiprofessional assessment or further therapy. In another respect it may add to the credibility of the findings by demonstrating change in

process as well as outcome. Either way concomitant services require assessment, and are explored in detail in the following chapter.

Donabedian's framework has been validated through its extensive use in the UK, where it has been a consistent feature of many quality assurance initiatives and evaluation strategies. It has been recognised however that the assignation of factors considered important in an evaluation to either component of the framework may be problematic, particularly in agreeing a distinction between structure and process (Closs and Tierney, 1993). Whilst its simplicity may have contributed to its success, the potential to neglect consideration of other factors that may be important in establishing the success of a health care intervention or programme cannot be underestimated. The emphasis of the framework is the linear relationship between the three constructs, emphasising the importance of causality in defining links between health care intervention and outcome. Whilst the framework acknowledges the importance of environmental and resource issues that are relevant to a health care setting in shaping those links, factors that are peculiar to any given patient or their social world fall outside the remit of structure, process or outcome. Where the consequences of disease are complex, and are heavily dependent on the physical, emotional and social resources available to a sufferer, as in stroke, an over-reliance on this framework is unsatisfactory. For example, consideration should be given at recruitment to 'patient factors' that do not fall within either construct, for example presence or absence of a carer, type of residence.

Although the second theoretical framework, the International Classification of Impairments, Disease and Handicap (WHO, 1980) has recently undergone development, the earlier classification of pathological changes leading to

impairment, disability and handicap may also be used to organise the assessment domains that are being considered in this study (Table 8.4). The framework, which has been considered in detail in chapter three, specifically focuses on the consequences of disease, and as such can only be used to consider patient outcomes.

This classification of outcome domains to some degree reflects the nature of the study intervention, which is educative and supportive in nature. The intervention is not concerned with pathology per se. Depression has been classified as an impairment, in that it is a consequence of stroke in the widest sense. Whether depression is due to stroke pathology, or the overwhelming catastrophe of the disease is unclear. Whilst the classification of patient dependence as disability is relatively easy, the same cannot be said of perceived health, socialisation as indicators of handicap. Whilst these outcome domains fail to recognise the full complexity of this factor, and in particular the role of the social environment in which recovery can take place, they are relatively holistic in nature when compared with traditional assessment tools for disability. Table 8.4 demonstrates that, accepting these reservations, some representation across the ICIDH framework has been achieved in the selection of outcome domains.

In summary, the choice of assessment domains in this study has been influenced by the prevailing research agenda in stroke rehabilitation, by attempting to include both assessments of disability and the assessment of more global psycho-social consequences of stroke. The choice of assessment tools was also influenced by the previous clinical studies of related interventions. The degree to which these choices have influenced the context of the study, in particular the views of

different stakeholder groups and the wider social consequences of the disease, will be discussed in the following chapters of the thesis.

Assessment tool performance

Having established the domains for assessment, the selection of assessment tools can be undertaken. The importance of ensuring synergy with earlier related research to aid future meta-analysis has already been discussed.

In addition to the research and theoretical issues that are important in informing the selection of assessment tools, the practical and cognitive requirements for those who are completing the tool need to be considered. The relevance of an assessment tool must be weakened if low scores represent an inability to complete a questionnaire in the desired format. Whilst this is perhaps even more the case given the range of consequences of stroke, it is often neglected in papers discussing tool selection. In this study, previous reports of the use of assessment tools in the stroke population, coupled with established modes of administration were also used to confirm the suitability of the final selection of assessment tools. There are however two further issues which need to be considered in the selection of individual assessment tools.

Validity and reliability

The performance of an assessment tool can be described in terms of its validity and reliability. Here, validity refers to the degree to which an assessment tool assesses what it intends to assessed, and can be indicated in three ways (Wade,

1992; Robson, 1993). Construct validity refers to the degree to which results from the assessment tool in question correlate with other variables, where a relationship between the domains covered in those tools is known to exist. By default, this stresses the importance of rigorous development work in the construction of an assessment tool. A similar indication of validity, criterion-related, relies on the existence of a 'gold-standard' assessment tool against which a tool in development can be assessed. Little information can be gleaned from the literature as to what benchmarks can be used to identify a gold-standard, and in stroke rehabilitation such an assessment tool is unlikely to exist: there are few tools, if any, that have not been the subject of criticism in the literature. Content validity is a further aspect of validity that depends on the use of a strong theoretical framework to guide the development of an assessment tool.

Where reports of assessment tools that consider validity can be found, limitations with the three approaches can be identified. The examination of previous use in related studies, and the experiences of those researchers who have used those assessment tools, can however usefully contribute to the justification of the selection of specific assessment tools in research.

Reliability refers in essence to variation in the performance of an assessment tool. For the purposes of this study variation can be considered in two ways: arising from the patient or from the assessor. Intra-rater reliability can be assessed by the degree of association between two separate ratings on the same subject. The length of time between assessment points in a study of reliability will depend on the domain of study and its anticipated stability.

Variation between the data obtained by different assessors on the same subject is termed inter-rater reliability. Similarly this can be assessed in the field, however the reduction of time between the assessment points is warranted to minimise the risk of any real change in the assessment domain.

Sometimes referred to as an aspect of validity, responsiveness refers to the ability of an assessment tool to detect important changes in health status (Fitzpatrick, Davey, Buxton *et al*, 1998). Various approaches to numerically estimating the responsiveness of assessment tools can be found in the literature, however none refer to the central issue: what counts as an important change? Progress with this issue in the development of evaluation research methodologies would appear to be slow. For example, one recommendation to consider responsiveness includes making observations at 'separate times when there is good reason to think that changes have occurred that are of importance to patients'. (Fitzpatrick, Davey, Buxton *et al*, 1998 p32). In stroke rehabilitation research specifically, Wade (1992) suggests that the responsiveness of assessment strategies may be enhanced by the use of several, complementary assessment tools. A second proposal refers to the specification of discrete objectives of rehabilitation, such as independence in a wheelchair, which can easily be observed. Whilst this approach may be beneficial where objectives of rehabilitation can be readily identified and agreed, the limitations in terms of the wider purpose of rehabilitation are evident.

Assessment tools

A range of outcome measures were used to explore the impact of the intervention at three months and twelve months. The outcome assessment tools used were:

- Barthel Index (patient)
- Nottingham Health Profile (patient)
- Beck Depression Inventory (patient)
- Frenchay Activities Index (patient)
- Caregiver Strain Index (principal carer)

The Barthel Index

The use of the Barthel Index (BI), which purports to focus on activities of daily living, is a frequent feature of research in stroke rehabilitation, and its preference over other indices has been strongly advocated (Wade, 1992). Frequently, activities of daily living in this sense will include toileting, mobility, cleanliness, feeding and dressing. The activities that constitute daily life can therefore be firmly located in models of disability. This is in fact a major criticism of this type of index: that it adopts a very reductionist view of 'daily life', and is in essence arbitrary as it lacks a strong theoretical foundation. Whilst the BI has been referred to as a measure of basic activities of daily living (Gompertz, Pound and Ebrahim, 1993), it is probably preferable to refer to the BI as an indicator of physical dependence.

The literature includes numerous testaments to the close relationship between the development of the index and clinical practice, with claims that this reinforces the validity of the instrument (Wade, 1992). Whilst the original article in which the index is described contains no information on its development (Mahoney and Barthel, 1965), Wade (1992) identifies the correlation of index scores with clinical impression as justification of its validity. The weakness in this argument is the

assumption that clinical practice is necessarily serving the real interests of those requiring rehabilitation. A reliance on measures that focus on dependence may be seen to suggest that the goal of rehabilitation is to promote a level of independence sufficient enough to allow the passage of the patient through the 'rehabilitation system', rather than facilitating coping, adaptation and quality of life.

The extensive use of the Barthel Index in stroke rehabilitation research has however enhanced its perceived validity: low scores predict discharge destination after hospitalisation and other indicators of recovery (Shah, Cooper and Maas, 1991; Wade, 1992). As a consequence it has been advocated as the universal standard for the assessment of activities of daily living (Wade and Collin, 1988; Ebrahim, 1990).

The tool itself is composed of 10 items (Table 8.5), with varying response options. Each response option includes a descriptor to aid completion. Whilst the maximum score is 20, it has been postulated that a change of two points on the scale, or a change from dependent to independent in any one item, represents a real clinical change (Collin, Wade, Davies et al, 1988). This contrasts with Wade (1992) who maintains that a change in score of four out of twenty is clinically significant. Specifying any overall change in score is problematic however, as it would appear that a 'change in ability at the upper level of the scale is three times greater, unit for unit, than an apparent similar change in the middle of the scale' (Tennant, Geddes and Chamberlain, 1996 p306). This would suggest that a clinically significant change in Barthel Index score should be only be used with

caution as the primary outcome in power calculations, and where the tool is used in evaluation research, non-parametric statistical tests are more appropriate.

Wade (1992) reports that the index has reasonable reliability (inter-rater and intra-rater), which is not significantly affected by the mode of administration. In fact empirical studies of intra-rater reliability have been promising, with Spearman's rho equal to 0.92 ($p < 0.05$) for test and retest over two weeks.

Copyright of the tool appeared to rest with the journal of original publication, and no fee was required for its use.

The Nottingham Health Profile

The Nottingham Health Profile (NHP) is a well established questionnaire that measures respondent perceptions of general health in the following domains: energy, emotional reaction, physical mobility, pain, social isolation and sleep. Originally the questionnaire consisted of two sections, both containing questions with a binary response format. The first section contains 38 items within each domain to which a respondent indicates agreement or disagreement with a statement. The second section, which is no longer recommended for use, contained a number of questions that relate to wider aspects of life such as employment, social life and home life. Again response options were binary, but scores did not contribute to the overall measurement of quality of life. Response options in the first part of the tool are weighted, with a maximum score of 100 in each domain. High scores indicate agreement with statements describing ill health and therefore represent poorer outcomes. The overall score that represents

perceived general health is a summation across each domain, with equal weighting given to all six domains. Its use is currently recommended as follows:

- the evaluation of health and social care interventions
- monitoring subjective health in individual patients
- an epidemiological health assessment tool (Hunt, McKenna and McEwen, 1980)

The Nottingham Health Profile was developed in the late 1970s, underpinned by field work undertaken in the healthy population to identify statements describing the typical effects of ill health. An initial pool of over 2,000 statements were identified and reduced to 138 after eliminating those items felt to be inappropriate. This item pool was further refined after it was decided to remove negative statements, and to leave only those items that could be answered in binary format. The Nottingham Health Profile manual reports an extensive list of validation studies, most studies employing some form of comparison to a reference group of 'known' health (Hunt, McKenna and McEwen, 1980). Retest studies of reliability in patients with osteoarthritis and peripheral vascular disease were shown to be encouraging with Spearman's rho ranging from 0.75 to 0.88 across the tool domains.

While use of the Nottingham health Profile is a frequent feature of clinical research that evaluates the effectiveness of stroke rehabilitation interventions (for example, Forster and Young, 1996), there is limited description of the performance of the Nottingham health Profile in a general stroke population, particularly where data is cross-referenced to clinical and other outcome data (Gompertz, Pound and Ebrahim, 1993). Where profiling has been undertaken, the

selection of relevant clinical indicators and other assessment tools, and the selection of measurement periods is difficult. For example, Nottingham Health Profile scores were correlated with the severity of physical ability at both one and six months (Ebrahim, Barer and Nouri, 1986). Physical ability in this case was rather crudely taken to be either an ability to walk or not. Whilst data was not distributed normally, the mean scores of Nottingham Health Profile domains for patients (n=159; mean age 68.8 years) one month after stroke were presented to aid comparison across studies, and are reproduced in Table 8.6.

Weak correlations were found between scores at one and six months, with patients scoring highly at one month more likely to score highly at six months. This correlation was stronger for emotional reaction, pain and social isolation. Further analysis of the interaction of other factors such as changes in physical mobility or place of residence was not undertaken. Coupled with the complexity of clinical recovery from stroke, particularly in the first six months, this profile of Nottingham Health Profile scores is difficult to explain with any degree of certainty. In general terms, it would appear that higher Nottingham Health Profile scores were strongly related to poorer physical disability. This association was even stronger when physical function either improved or decreased. It has been postulated that any changing health status may accentuate negative perceptions of general health. While this may or may not be the case, this finding would strongly indicate that the Nottingham Health Profile measures domains other than physical ability, and that its use in rehabilitation research, coupled with more specific measures of physical ability, is recommended.

Whilst the Nottingham Health Profile was intended to be self-administered, other potential modes of delivery have been highlighted, including administration by an interviewer. Ebrahim, Barer and Nouri (1986) report little difficulty with completion of the Nottingham Health Profile, and favourable comparison with similar assessment tools such as the General Health Questionnaire, particularly in relation to the relative simplicity of design. Copyright is protected by Galen Research, and a fee payable for its use.

The Beck Depression Inventory

The Beck Depression Inventory (BDI) (2nd edition) is a well established assessment tool that can assess the severity of depression in a given population. The domains identified within the tool are given in Table 8.7, and were selected from verbal descriptions of depression by psychiatric patients, rather than any formal theoretical representation of depression (Beck, Steer and Brown, 1996).

Each domain corresponds to one item on the questionnaire, with four response statements graded to severity scoring from 0 to 3. A total score can be computed from a simple summation across all 21 items. For use as a diagnostic tool, the diagnostic criteria specified in Table 8.8 are suggested from the results of US cohort studies.

The validity and reliability of the Beck Depression Inventory rest primarily in the extensive testing of the tool during its development (Beck, Steer and Brown, 1996). Whilst much of this work was undertaken in the US, and principally focused on the performance of those with diagnosed depression and other

psychiatric disorders, the tool has been often been employed in stroke rehabilitation research.

The Beck Depression Inventory can be administered for either self completion, or within an interview format. Time required for completion is suggested to be between 5 and 10 minutes, and the provision of response sets in hardcopy to respondents is suggested. Copyright is protected by the Psychological Corporation, and a fee payable for its use.

The Frenchay Activities Index

The original aim of the Frenchay Activities Index (FAI) was to provide a brief scale, capable of measuring 'changes in quality of life following a sudden disabling illness' (Holbrook and Skilbeck, 1983 p166). Whilst the focus on quality of life may be somewhat naïve, the content of this tool eventually focused on the assessment of everyday activities deemed to be representative of normal living. Factor analysis demonstrated the presence of three domains in the Frenchay Activities Index: domestic chores, leisure and work, and outdoor activities. Whilst a major weakness of the tool can be found in the original intuitive selection of items considered to be representative, the FAI is a consistent feature of recent evaluation research in stroke rehabilitation.

In a comprehensive assessment of the performance of the Frenchay Activity Index, validity was established by comparison with stroke patient (n=976) scores on a range of other assessment tools, including the Barthel Index and the Wakefield Depression Inventory (Wade, Legh-Smith and Langton Hewer, 1985).

Whilst some sex differences were identified on certain items, these differences were not statistically significant. It has been postulated however that the Frenchay Activity Index may be susceptible to culture differences, where the performance of activities of living may be influenced by gender and social roles.

Copyright of the tool appeared to rest with the journal of original publication, and no fee was required for its use. Attempts to contact the authors for permission to use the tool were unsuccessful.

The Caregiver Strain Index

The Caregiver Strain Index (CSI) was developed with reference to both scientific literature and extensive exploratory research. A total of 13 items, binary in nature, were included in the final assessment tool. Validity was established by reference to clinical indicators and other established assessment tools, including the Affect Balance Scale, Profile of Mood States and the Katz Activity of Daily Living Index (Robinson, 1983).

Copyright protection for the Carer Strain Index rests with the original journal of publication, and no fee was payable for its use. Despite having retired, the tool's author granted permission for its use, and supplied original material relating to the development and testing of the tool.

Assessment timeframe

Despite calls to extend the assessment of patients in stroke rehabilitation trials further than one year (University of Leeds, 1992), usual practice in stroke rehabilitation research would suggest that patients are assessed at three, six and twelve months. Establishing a timeframe for assessment requires balancing the resources available to fund assessment, the dangers of multiple assessment, and the ability to detect important changes. A decision was taken to focus on a three and twelve month assessment. It was anticipated that this would enable short term issues related to the process of discharge and readjustment to stroke, and longer term recovery to be captured.

Organisation of assessment

All of the chosen assessment tools had been delivered, or were reported as suitable for administration in an interview. Whilst it may have been easier from the point of view of the investigator to administer assessments indirectly, for example by post, the potential communication difficulties that may have faced the study population were thought to be significant enough to warrant assessment in an interview format despite the extra costs this mode of administration would incur.

The Nottingham Health Profile, Barthel Index and Frenchay Activity Index were applied at each assessment point. The Caregiver Strain Index was omitted at randomisation as it was unlikely that the burden of the disease for carers would be manifest in the immediate post-stroke period. Similarly the Beck Depression

Inventory was also omitted at randomisation. Whilst evidently stroke will precipitate immediate psychological effects, including shock, fear and anxiety, these were not the focus of the study intervention. These two omissions had the added benefit of limiting the burden of assessment for patients and carers at a particularly critical time in their experience of stroke.

After consent had been obtained, general demographic data and baseline assessments were completed by the author. At the three and twelve month follow-up, all assessments were applied at the patients place of domicile by a research assistant. The assessment tools were incorporated into an assessment book, which included a script to ensure that interviews were as standardised as possible. A copy of the assessment book is included in Appendix 6. The assessment book also included some space for debriefing so that the context of interviews and any untoward occurrences could be recorded.

Attempts to ensure the quality of assessment in the trial were made in the following ways:

- where available, exemplars and criteria for scoring were included in the assessment handbook
- preliminary training in interview technique was undertaken by the research assistant, including participation in mock interviews with healthy volunteers
- peer supervision of interviews was undertaken by the author on six occasions during the trial.

After each interview a debriefing discussion was used to discuss the interview with particular reference to communication skills and assessment. Inter-rater reliability was not however assessed as part of this process.

Sampling

An inclusive sampling frame was proposed that attempted to balance the effect size sought with the resource implications of the development. The closest evaluation, in terms of intervention and population, to guide the development of the sampling strategy was that of specialist nursing support for stroke patients in the community (Forster and Young, 1996). This showed that 30% of subjects in the control group scored 30 or more on the Nottingham Health Profile twelve months after randomisation. This score has been shown, when studied with the General Health Questionnaire to indicate a depressed mood (Ebrahim, Barer and Nouri, 1986). A decision was taken to plan to detect a reduction in the prevalence of depressed mood assessed by the Nottingham Health Profile total score from 30% to 15%, that is a reduction of the prevalence of depressed mood by one half.

Inspection of statistical tables demonstrated that in order to detect a difference between the groups at 12 months, with a study power of 80% and a 5% two-sided significance level, 121 patients were required in each group (Machin and Campbell, 1987 p22). The trial intervention was unlikely to pose any threat to patients, and no adverse effects were anticipated. For these reasons no interim analyses or stopping rules were planned.

Method of randomisation

To ensure similarity between the two groups in key areas, randomisation was stratified by admitting hospital, first or subsequent stroke, destination on discharge and levels of functional dependence on discharge. One of the key

purposes of the trial intervention was to facilitate adaptation to the consequences of stroke through the development of coping skills. It was thought therefore that previous stroke may have enabled the development of pre-intervention coping strategies. Discharge destination, home or institutional care, would have a significant effect on the availability of services, and in particular nursing care. The findings from the Forster and Young (1996) study were generally disappointing, an improvement in social outcome in a sub-group of patients - those who scored between 15 and 19 on the Barthel Index. It was decided to ensure that this potential group of patients were equally distributed across both trial arms, and participants were stratified according to their Barthel Index score at recruitment (1-14 or 15-20).

Participants were randomly allocated by the author using an independent randomisation centre (University of York). The randomisation sequence was concealed. Randomisation was undertaken as soon after recruitment as possible, during office hours. The stroke nurse was informed of the randomisation on the next working day, and a record made in the patient's hospital notes. On randomisation, each patient was assigned a trial registration number from the computer database which was used to conceal and collate trial documentation.

Blinding

Whilst the incorporation of blinding into the design of a clinical trial may be considered a testament to the internal validity of a clinical trial, where interventions are complex and obvious to those that receive them it is notoriously difficult to achieve. In a pragmatic trial blinding is often impractical, and in some

respects undesirable, particularly in relation to blinding the receipt of trial interventions by patients. So the only blinding that was attempted in this trial was in relation to outcome assessment.

The research assistant was only given access to a trial membership form (Appendix 7) on which simple demographic information was recorded. The date of admission to hospital and registration to the trial was also recorded to facilitate follow-up of length of stay, changes to planned discharge destination, and to plan appointments for follow-up assessment. The membership form did not contain any information relating to randomisation status.

Whilst it was hoped that to some degree the scripting of assessments would limit any informal conversation at interview, it was recognised that participants were likely to divulge the content of any formal care packages, and consequently whether stroke nurse follow-up was provided or not. A question was therefore included in the assessment debriefing form requiring the research assistant to assess the participants randomisation status. It was felt necessary to only include this question at the three month assessment.

Of the 176 assessments undertaken at three months, the success of blinding question was omitted where only a partial assessment (Barthel Index and/or Frenchay Activities Index) was completed over the telephone with a nursing home matron, or a carer. Thus 87 patient assessments were eligible for consideration of blinding. The question was omitted in a further 7 instances, leaving 80 blinding questions for which a response was recorded. The research assistant correctly

identified the patient's randomisation status on 64 (80%) occasions. Attempts to blind the assessment of patient outcome were therefore ineffective.

Data entry

At randomisation, the hospital number of the patient was entered on a personal computer by the researcher using the Statistical Package for the Social Sciences (Version 10), thus producing the Trial Registration Number. Assessment data was subsequently entered by the author, who was blinded to the randomisation status of the patient, directly from the assessment books. When the entry of assessment data was complete, baseline data, including the randomisation status were added to the database.

Data analysis plan

As with many clinical trials, the inclusion of relevant domains of assessment requires balancing with the risks of allowing a Type I error, where the null hypothesis is falsely rejected. This risk increases as the number of statistical comparisons increases. Current good practice strongly advocates for the detailed description of all planned analyses during the early stages of trial design (Pocock, 1983). The data analysis plan for this trial was subject to peer review during the design of the trial, and is reproduced in Appendix 8.

The plan describes four main statistical analyses. Initially baseline equivalence was checked using the appropriate statistical tests. Between group comparisons for all key variables at three and twelve months were then completed. Where

possible, changes from baseline rather than actual scores were studied. As an intention to treat approach to data analysis was adopted, the effect of missing data was then checked in two sensitivity analyses. Lastly the relationship between intervention intensity and the outcomes of patients in the experimental group were explored.

Statistical methods

The key statistical principles that have underpinned this study relate to an acceptable level of type 1 error, which has conventionally been set at 0.05, and which error relates to the rejection of a true null hypothesis. Additionally, no assumption about the effects of the trial intervention were made, and so all significance tests are two sided (Bland, 1995).

The data as a whole were distributed with little normality for all variables. Measures of central tendency for selected variables are provided in Table 8.9. Distributions were checked both numerically and graphically. The non-normal distribution was expected given the limited score profiles of most tools, and effects of weighting in the Nottingham Health Profile, particularly where some domains measured by the tool are assessed by a small number of items. Accordingly non-parametric statistical analyses were used in the majority. Descriptive statistics focused on the median and inter-quartile range, with the Mann Whitney test used to explore differences between groups. This is the non-parametric alternative to the t test, relying on ranking rather than normal distribution. It is however slightly less powerful than the t test for normally distributed data, and, crucially, does not provide information on the size of a

difference between two variables (Bland, 1995). For this reason, the overall score on the Nottingham Health Profile will also be described and analysed using a mean and confidence interval.

Where relevant and possible, analysis of the changes in outcome scores over time was also examined with the Mann Whitney test. The threshold criteria for engaging in this analysis were correlations between scores of 0.5 or greater (Matthews, 2001). The non-parametric correlation coefficient, Spearman's rho, was used to assess the applicability of examining changes in data.

For checking the distribution of binary variables between groups, the chi-square test was used. This statistic, a function of the distribution of observed and expected values within the variable, provides only an indication of statistical difference: it does not provide information on the strength of that difference. Its use therefore needs to be placed in context by the inclusion of appropriate descriptive statistics when reporting results. Additionally the chi-square statistic is susceptible to the effects of the size of a study, where the distribution of a calculated chi-square statistic is closer to its theoretical value when expected frequencies are high. Accordingly, a minimum expected cell frequency of five was adopted as a minimum threshold to assess the validity of the test in practice.

Associated studies

The methodological principles underpinning this study have recognised the relevance of post-positivism in addressing some of the major criticisms of the more traditional positivism. There is a recognition that 'no matter how faithfully

the scientist adheres to scientific method, research outcomes are neither totally objective nor unquestionably certain' (Crotty, 1998 p40). The products of research are therefore cumulative, rather than definitive, due to the real world nature of undertaking evaluation research. Triangulation and integration of findings across studies has been proposed as a means of providing different perspectives on an evaluation topic, representing the views of different stakeholders. In this way an integrative assessment of treatment effectiveness can be made. In this thesis, the clinical trial will only provide information on the relative merits of the intervention as compared with usual clinical practice. The consideration of these merits will however be largely limited by the breadth and robustness of the chosen measures in representing stakeholder perspectives. The trial as described so far will provide only limited information on either the acceptability or professional requirements of providing the intervention in clinical practice. These issues will be considered in separate, but complementary studies.

The description of the intervention reinforces the complex nature of its implementation. There is a minimum intensity of intervention provided to all patients in the experimental group, with the capacity for some patients to receive more. The precise level of intervention for individual patients was determined by the stroke nurse in accordance with the theoretical drive to responsiveness and a focus on individual need. Whilst the design conforms to the principles set out in the Medical Research Council guidance for trials of complex interventions (MRC, 2000), there is scope to consider the following issues:

- the relationship between intensity and patient recovery
- the factors that shaped the delivery of the trial intervention.

These issues, coupled with the acceptability of the intervention, were considered in three associated studies.

Associated study to explore intervention acceptability

This associated study aimed to determine the nature of the interaction between stroke patients and carers and a new nursing role in stroke rehabilitation, the stroke nurse. Specifically the objectives were to explore:

- to identify components of the role that were perceived as acceptable by patients and carers, and
- to identify ways in which the role may be enhanced

The purpose of this study was not to generate generalisable information about satisfaction with the intervention, rather to identify possible explanations for its effect on patient outcomes. The study required a research approach that facilitated free expression of perspectives from both patients and carers, and consequently followed the phenomenological tradition in nursing research. In this way a rich description of attitudes towards and experiences of the intervention could be constructed. Data were therefore collected in an unstructured interview with participants in their own homes. In essence, patients and their carers were asked to discuss their care, with an initial open question: how did you find the stroke nurse's contribution to your care? This type of study inevitably means that the number of informants will be small. For this reason and the limited funding available for this study, the sample size was six patients and their caregivers.

Interviews were conducted by the research assistant who, although having a stake in the study, was deemed to be more detached from the study than the author. The interviews were tape-recorded, transcribed in full and then analysed by the author to identify main patterns of response. Standard approaches to the analysis of qualitative data were used (Burnard, 1991).

Associated study of the sub-types and intensity of trial intervention

The package of interventions provided to patients in the trial experimental group was monitored through regular analysis of documentation used by the stroke nurse in performance of trial interventions. Initially, trial documentation was trawled and the number of contact episodes between patients and the stroke nurse counted. The length of time over which these episodes occurred was also identified. A correlational analysis of the relationship between contact between stroke nurse and patient, and the length of time the trial intervention was provided to patients, and the perceived health scores on the Nottingham Health Profile was undertaken.

All interventions were identified and then categorised thematically using an established theoretical description (Burton, 2000c). The method for the analysis of data in this study were similar to those used in the intervention acceptability associated study. From this classification the distribution of three major types of interaction (care giving, care management and the nurse as therapeutic practitioner) in the trial were computed.

Associated study to examine the practice context of the trial intervention

This associated study aimed to

- identify the professional and practice issues that shaped the development of nursing practice within the stroke nurse role
- explore the personal and organisational strategies that supported role development
- identify extrinsic factors that influenced the development of nursing practice

Initial inspection of the literature has failed to identify a robust theoretical framework to guide the deductive investigation of role development. An inductive approach was therefore required that enabled the delineation of key themes that reflected the practitioners world.

Reflection has been described as a process that enables the surfacing of nursing action from a complex and ‘murky’ therapeutic milieu (Schön, 1983). In recent years reflection has become part of the nursing vocabulary, and is a consistent feature of continuing professional development activity. Its purpose is to delineate the real world of a practitioner’s decision-making where established theories and approaches are translated to individual ends. Traditional approaches to reflection are termed ‘single-loop’, and require the practitioner to explore critical incidents (Greenwood, 1998). The focus is on the identification of alternative courses of action that may lead, in future, to the same desired outcomes. Their use has been criticised as being too simplistic to empower the practitioner to change practice. Double-loop reflection, however, also focuses on the complex inter-relationships

between individual norms and values, and the professional structures that influence these norms and values, and ultimately nursing action.

On commencement of the trial, the stroke nurse was issued with a supply of critical incident forms so that significant events which influence practice can be recorded. These critical incidents and the operational aspects of the role were also explored in four interviews between the researcher and practitioner. Although interviews were open to maximise free expression, an adaptation of the double-loop reflection framework proposed by Smyth (1989) was used to guide discussion:

- Description of practice
- Aims and goals of practice
- Beliefs about the aims and goals of practice
- The values and assumptions that underpin these beliefs
- Origins of values and assumptions
- The social norms reflected in values and assumptions
- Power relationships in social norms, values and assumptions
- Whose interests are served in these power relationships
- Constraining influences on beliefs, values and assumptions

Interviews were tape-recorded and transcribed, but all data were subjected to synthesis and thematic profiling (Morse and Field, 1995). Validity of interpretation was assessed through regular feedback and review of the findings by the practitioner. The issues reflected in the interview guide were condensed into three key themes

- aims of clinical practice

- values and assumptions
- power relationships in clinical practice

for the presentation of findings.

Triangulation and post-hoc evaluation

The working methods demonstrate a research plan that is complex, with four inter-related studies. The process of triangulation was described in the previous chapter. In this thesis, the findings of associated studies have essentially been used to provide a context for the presentation and discussion of trial findings.

Study management

The study was strategically managed by a multi-stakeholder steering group to ensure relevant to the needs of the National Health Service, and to guarantee entry to clinical areas. Group membership included representation from trust management, the University hosting the research, and members of the multidisciplinary team at the relevant clinical sites. The terms of reference for the steering group included the provision of a resource to the lead investigator capable of informing the strategic and operational development of the research, and contributing to the dissemination strategy. The group met a total of six times during the research, providing advice and support on a number of key issues including ethics and informed consent, professional indemnity, and training and management support for the stroke nurse.

Item	Criterion	Compliance
Title and Abstract	To include how participants were allocated to intervention	'Randomised' specified in thesis abstract
Background	Scientific background and explanation of rationale	Theoretical underpinnings and systematic review of therapeutic nursing included in thesis
Participants	Eligibility for participants, study settings and locations in which data were collected	Stated in Chapter 8
Intervention	Detailed descriptions of interventions, including how and when they were administered	Stated in Chapters 6 and 8
Objectives	Specific study objectives and hypotheses	Stated in Chapter 8
Outcomes	Clearly defined primary and secondary outcome measures, including details on how the quality of assessment was assured	Stated in Chapter 8
Sample size	How sample size was determined, and explanation of any stopping rules	No stopping rules. Power calculation based on clinically important changes in primary outcome. Desired sample size not achieved in practice.
Random sequence generation	Methods used to generate the random allocation sequence	Use of an independent randomisation centre
Allocation concealment	Methods used to implement the random allocation sequence	Use of an independent randomisation centre
Implementation	Who generated the allocation sequence, enrolled and assigned participants to their groups	All patients recruited and enrolled by principal investigator.

Table 8.1. Checklist of items to include when reporting a randomised trial as applied to this thesis.

(Table 8.1 Continued)

Blinding	The degree to which the blinding of intervention and outcome assessment were achieved	Intervention not blinded as pragmatic trial. Blinding of outcome assessment by research assistant attempted.
Statistical methods	The methods used to compare groups, and any sub-group analysis	A priori data analysis plan specified
Participant flow	Details of the flow of participants through each stage of the trial	Diagram of participant flow produced in Chapter 9
Recruitment	Dates defining the periods of recruitment and follow-up	Reported in Chapter 9
Baseline data	Baseline characteristics of each group	Reported in Chapter 9
Numbers analysed	How an 'intention to treat' was implemented in the analysis of data	A priori data analysis plan specified
Outcomes and estimation	Summary and the precision of results for each primary and secondary outcome	Presented in Chapter 10. Primary outcome considered in terms of mean and 95% confidence interval
Ancillary analyses	Descriptions and justification for any ancillary analyses	One ancillary analysis included. Detailed in Chapter 9
Adverse events	Any adverse events or side-effects in either group	No adverse events or side-effects detected
Interpretation	Interpretation of the results in the context of the internal validity of the trial	Undertaken in Chapter 10
Generalisability	External validity of the trial findings	Undertaken in Chapter 10

Table 8.1. Checklist of items to include when reporting a randomised trial as applied to this thesis.

(Table 8.1 Continued)

Overall evidence	Interpretation of the results in the context of the internal validity of current evidence	Undertaken in Chapter 10
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Table 8.1. Checklist of items to include when reporting a randomised trial as applied to this thesis.¹

¹ (Adapted from Moher, Schulz, Altman *et al* 2001).

Study	Assessment domains	Assessment tools
Folden (1993) ¹	Perception of self-care efficacy	Exercise of Self-Care Agency
Forster Young (1996)	Functional ability	Barthel Index
	Social activity	Frenchay Activity Index
	Perceived health status	Nottingham Health Profile
	Caregiver strain	Caregiver Strain Index

Table 8.2. Overview of outcome assessment domains and tools used in studies identified in the systematic review.

¹ The Revised Barthel Index was also used to assess outcome, however data are not reported.

Structure	Process	Outcome
Admitting hospital	Treatment arm	Patient perceived health
Available services	Length of stay	Patient dependence
Intervention costs	Intensity of intervention	Patient depression
	Concomitant services	Patient socialisation
		Carer strain

Table 8.3. Classification of all proposed study factors using Donabedian’s (1966) Theoretical Framework.

Impairment	Disability	Handicap
Patient depression	Patient dependence	Patient perceived health Patient socialisation

Table 8.4. Classification of patient outcome domains using the ICIDH (WHO, 1980)

Item	Maximum score
Bowels	2
Bladder	2
Grooming	1
Toilet	2
Feeding	2
Transfer	3
Mobility	3
Dressing	2
Stairs	2
Bathing	1

Table 8.5. Composition of the Barthel Index

Domain	Score ¹
Energy	35
Emotional reaction	21
Physical mobility	21
Pain	11
Social Isolation	20
Sleep	21
Total	129

Table 8.6. Mean scores in NHP domains in a group of patients (n=159) one month after stroke (Ebrahim, Barer and Nouri, 1986).

¹ Standard deviations not published.

Beck Depression Inventory Domains	
1	Mood
2	Pessimism
3	Sense of Failure
4	Self-Dissatisfaction (anhedonia)
5	Guilt
6	Punishment
7	Self-Dislike
8	Self-Accusations
9	Suicidal Ideas
10	Crying
11	Irritability
12	Social Withdrawal
13	Indecisiveness
14	Body Image Change
15	Work Difficulty
16	Insomnia
17	Fatigability
18	Loss of Appetite
19	Weight Loss
20	Somatic Preoccupation
21	Loss of Libido

Table 8.7. Domains of the Beck Depression Inventory

Total Score	Range
0 – 13	Minimal depression
14 – 19	Mild
20 – 28	Moderate
29 – 63	Severe

Table 8.8. Diagnostic Criteria for the Beck Depression Inventory

Variable	Minimum		Maximum		Mean		Skewness (Standard Error)	
	Control	Exp	Control	Exp	Control	Exp	Control	Exp
Barthel Index score at randomisation	0	2	20	20	12.92	13.21	-0.53 (0.26)	-0.32 (0.26)
Total NHP ¹ at 3 score months	12.57	0.00	522.12	515.67	229.47	187.43	0.56 (0.26)	0.73 (0.26)
Change in FAI ² score from randomisation to 12 months	-24	-30	3	5	-11.24	-8.46	0.10 (0.40)	0.52 (0.4)
Change in BDI ³ score from 3 to 12 months	-9	-11	10	18	-0.36	-1.53	0.56 (0.32)	1.63 (0.31)
Change in CSI ⁴ score from 3 to 12 months	-5	-4	3	3	-0.33	-0.62	-0.87 (0.39)	-0.01 (0.39)

Table 8.9. Central tendency of selected variables

¹ Nottingham Health Profile

² Frenchay Activity Index

³ Beck Depression Inventory

⁴ Caregiver Strain Index

Chapter 9

Results

Introduction to the chapter

Having established the methodology and research methods in previous chapters, this chapter will focus on the presentation and analysis of key data. Whilst reference will be made to the findings across the associated studies described in the last chapter, the relationship of study findings to the body of evidence as a whole will not be undertaken until later in the thesis. The purpose of this chapter is to present an analysis of the data to infer, and assess the validity of, the key implications of this study.

Summaries of numerical data are presented mostly in tabular format, with both the actual numbers of patients and the corresponding proportions detailed together (Moher, Schulz and Altman, 2001). Where indicated in the trial analysis plan (Appendix 7), statistical tests have been carried out. The results of these tests are only displayed when the threshold for significance is borderline or has been reached. In this case, the name of the particular test is detailed together with the actual significance level at the foot of the table. It can be assumed that all significance tests were two-sided. Where relevant, numbers have been rounded to one decimal place: an exception is the Nottingham Health Profile which has been rounded to two decimal places. Qualitative data to contextualise the results is included in the text in italics, with the source of the data included in brackets at the end of each quote. The format for the presentation of data is summarised in Table 9.1.

In keeping with previous chapters, the CONSORT statement (Moher, Schulz and Altman, 2001) has continued to be used as a benchmark for the reporting of data.

Similarly additional material is included where necessary for reasons of academic rigour or the assessment of generalisability. Contrary to the CONSORT statement, the information on recruitment is presented before participant flow to assist the narrative flow.

Recruitment

The trial proper commenced at the end of September 1999, on completion of the training programme for the Stroke Nurse and pilot implementation study. Patients were recruited from this date from both hospitals A and B. Recruitment was stopped in April 2001, when funding for the study intervention ceased.

The first patient was randomised on 4th November 1999. As a consequence, the three month follow-up assessment of participants commenced in February 2000, and the twelve month assessment commenced in November 2000.

The final patient was recruited on 6th April 2001. All three month assessments were completed by July 2001, and twelve month assessments were completed by March 2002.

During the recruitment phase, a total of 221 patients were reviewed for possible inclusion in the trial. The management of these patients is detailed in the next section of this chapter. The exclusion criteria removed 39 patients. A decision was also taken to exclude one patient who could not communicate verbally or visually in English. Whilst not specified in the original exclusion criteria, it was felt this

issue would seriously affect the patient's ability to contribute to the trial in any meaningful way, either through assessment or receipt of the study intervention.

In the recruitment strategy, patients were usually identified after referral to the stroke nurse. Although some patients were identified after trawling the relevant wards of all hospitals to cover for when the stroke nurse was absent, all additional patients were subsequently referred to the stroke nurse on return. The target figure for patient recruitment was 242 which was not achieved in practice. Whilst considerable attempts were made to locate potential patients for inclusion, time factors inevitably meant that some patients were missed. The impact of this reduced sample size on the power of this trial to detect clinically important changes in patients is also discussed in the next chapter.

Participant flow

The flow of patients through the trial is detailed in Figure 9.1. The flowchart demonstrates that only one participant withheld consent for entry into the trial. Conditions for ethical approval from the two Local Research Ethics Committees allowed a patient's next of kin to provide informed consent when the patient's condition prevented them from doing so. This option was used in 89 out of 176 patients (51%) in the trial. The distribution of patient progress outcomes (continuing in the trial, withdrawal, lost to follow up) between the control and experimental group at each assessment point was not shown to be statistically significant by the chi-squared test.

The characteristics of those patients that completed the trial as compared to those that withdrew for whatever reason were subsequently checked using the t test, chi-square test or Mann Whitney test. Specifically, the characteristics checked were

- patient age (t test)
- patient sex (chi-square test)
- length of stay (t test)
- Barthel Index score at randomisation (Mann Whitney test)
- admitting hospital (chi-square test)
- previous stroke (chi-square test)

No statistical differences were detected.

Baseline data

The trial analysis plan demonstrates that although statistical examination of between group differences at randomisation was undertaken, this activity was intended only to confirm the robustness of the randomisation strategy. The results of statistical tests are not therefore reported, and there were no significant differences between the experimental and control group for all demographic variables measured at baseline. The actual characteristics of patients at randomisation are reported in this chapter.

The profile of all baseline binary variables is detailed in Table 9.2. There were more males than females in the trial, with this difference slightly more marked in the experimental group.

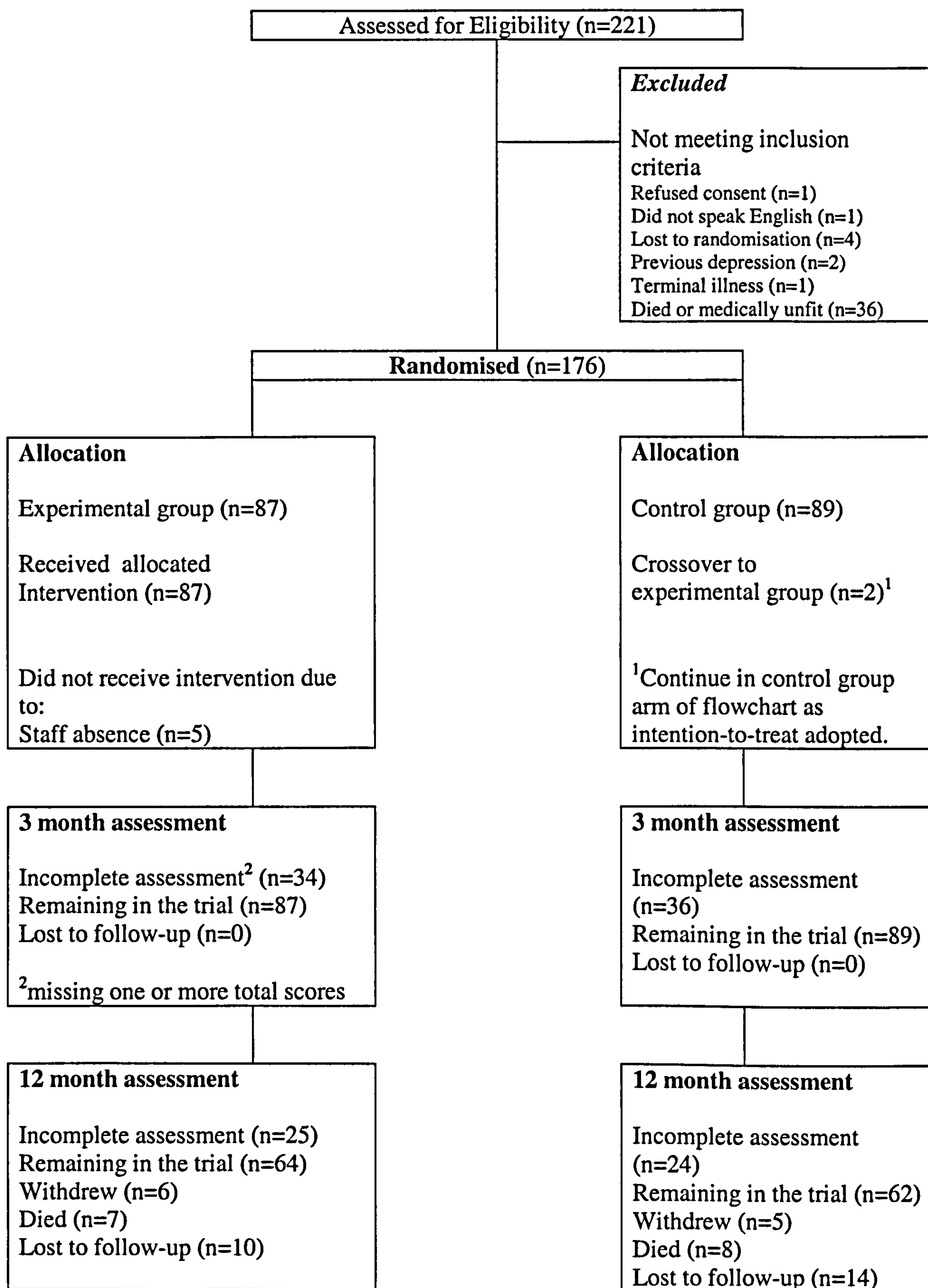


Figure 9.1. Flowchart of Patients in the Trial.

The proportion of patients admitted with a first stroke, and the admitting hospital was distributed consistently within both groups. The table demonstrates that the majority of patients in the trial were discharged to their home address, and that the distribution of those discharged into an institutional continuing care setting was consistent across both groups.

Whilst no relationship between the admitting hospital, patient sex or the destination on discharge from hospital was identified, subsequent analysis using the chi-square statistic demonstrated that patients in Hospital B were more likely to have been admitted with a subsequent stroke ($p=0.036$).

The mean age of patients in the trial was 75.25 years, and the distribution of ages in each group is detailed in Table 9.3. Typically for a sample of stroke patients, age was slightly negatively skewed. Accordingly, the distribution was also checked with the non-parametric Mann Whitney test, and also found to be non-significant.

89 patients recruited to the trial did not complete the Nottingham Health Profile, with 78 not completing the Frenchay Activity Index on recruitment (Table 9.4). Whilst the precise reason for non-completion was not recorded, this was usually due to the psychological or cognitive consequences of the stroke.

The distribution of patients across the control and experimental groups for whom Nottingham Health Profile and Frenchay Activity Index data was missing at randomisation was checked by the chi-squared test, and found to be non-

significant. The following characteristics of those patients without these scores at randomisation as opposed to those with scores were subsequently checked:

- patient sex
- first or subsequent stroke
- destination on discharge
- admitting hospital
- Barthel Index score on admission
- patient age at randomisation
- length of stay

Missing data for the Nottingham Health Profile and Frenchay Activity Index at randomisation was associated with a low Barthel Index score at randomisation (Mann Whitney U, $p=0.000$). In addition, using the t test demonstrated that missing data was also associated with increasing age ($p=0.033$) and increased length of stay ($p=0.036$). Both these scenarios are consistent with the clinical picture of stroke. Again, age was slightly negatively skewed, with length of stay slightly positively skewed. The non-parametric Mann Whitney test was used to confirm the relationship between missing baseline data with patient age and length of stay.

Examination of Table 9.5 demonstrates that the control and experimental group were equivalent in terms of the Barthel Index and Frenchay Activity Index scores at randomisation. The data would appear to indicate that the randomisation strategy was efficient in the production of similar groups for the trial, other than a small preponderance of patients with a subsequent stroke admitted to Hospital B.

89 of those patients without baseline Nottingham Health Profile or Frenchay Activity Index scores were consented by their next-of-kin. In eleven of these cases, a Frenchay Activity Index score was supplied by the next-of-kin. For the patients where the Nottingham Health Profile assessment was completed, the distribution of scores is detailed in Table 9.6. The table demonstrates that the two groups were consistent in scores on each sub-section of the Nottingham Health Profile

An in-depth examination of baseline data is essential to enable assessment of both the internal validity of the trial, and generalisability of the study findings. Multiple testing however increases the chance of a Type 1 error, resulting in the 'detection' of an erroneous statistically significant difference. It may be therefore that the relationship between admitting hospital and subsequent stroke is simply an artefact of multiple testing.

Numbers analysed

An intention to treat approach to the analysis of outcome data was adopted whereby all available data contributed to the performance of descriptive and inferential statistics. In addition, any patient assigned to the control group, who later received the study intervention (n=2), was analysed as a control group patient. Where patients in the experimental group did not receive any of the trial intervention (n=5), then similarly these patients were analysed as if they had been in the experimental group. A sensitivity analysis to explore the impact of missing data is included later in the chapter.

Outcomes and estimation

Due to the distribution of data within groups, and the nature of the outcome assessment tools used, the median and the interquartile range were used as the predominant descriptors of central tendency. One exception was made in the description of total Nottingham Health Profile scores in terms of means and confidence intervals to aid interpretation of the primary outcome.

Whilst absolute scores were considered, the analysis plan indicated that change in scores would be considered where the correlation between scores at assessment points and scores at randomisation were greater than 0.5 (Matthews, 2000). Correlation coefficients (Spearman's rho) from randomisation to both assessment points were calculated for the following:

- Barthel Index
- Frenchay Activity Index
- Nottingham Health Profile

All were found to have a correlation coefficient over 0.5, significant at the 0.01 level. Consequently analysis of the change in scores for these variables was also included. Where no data at randomisation was available, as for the Beck Depression Inventory and Caregiver Strain Index, changes in scores between the three and twelve month assessment points were considered.

Physical dependence

Physical dependence was assessed using the Barthel Index at randomisation, and at the three and twelve month assessment points (Table 9.7). At each assessment

point, the data demonstrates a consistent profile of Barthel Index scores across the control and experimental group.

Medians for changes in scores over time demonstrate consistency (Table 9.8), other than for a small decrease in physical independence at the twelve month assessment point for those patients in the control group. This was accompanied by a small increase in independence in the experimental group patients.

Whilst there were no statistical differences between the groups in the rate of change over the entire twelve month period, there was a statistical difference in the degree of change after three months. This is not easily observable through the median, and examination of a cross-tabulation of the rate of change in Barthel Index scores over time is more illuminating (Tables 9.9.1 to 9.9.3). Table 9.9.2 demonstrates that patients in the experimental group appear more likely to experience either no change in their Barthel Index score, or a modest improvement in score after three months.

Perceived general health

Patient perceptions of general health were assessed by the Nottingham Health Profile at randomisation, three months and twelve months. The assessment at three months indicated that whilst overall perceptions of health were similar across both groups, patients in the experimental group reported significantly lower levels of emotional distress and social isolation (Table 9.10). In addition, whilst only nearing statistical significance, perceived pain appeared to be higher for patients in the control group.

A similar profile of results was obtained at the twelve month assessment period (Table 9.11), where significant differences between the emotional reaction and social isolation sub-sections of the Nottingham Health Profile persisted. In this case however, the degree of difference between the control and experimental group in these two subsections is mirrored by a statistically significant difference in the total Nottingham Health Profile scores. The difference in the medians of the control and experimental group at the twelve month assessment period was 42.65 units. When contrasted with the full range of scores on the Nottingham Health Profile (from 0 to 600), this figure represents an improvement in perceived health of just over 7%.

The Nottingham Health Profile was only completed at randomisation by 43 out of 89 patients in the control group, and 44 out of 87 patients in the experimental group. Whilst the randomisation scores were high, indicating low levels of perceived general health, there appears to be little change in the total scores during the first three months of stroke (Table 9.12). Whilst both groups improved after three months, the amount of improvement in perceived general health was significantly higher in the experimental group.

To aid interpretation, and as the primary outcome, the mean and 95% confidence intervals for the Nottingham Health Profile scores and changes in scores were calculated (Table 9.13). Whilst the t test is more powerful than the Mann Whitney test (Bland, 1995), its use does require that assumptions about the normality of data are reasonably accurate. Visual inspection of histograms of the distribution of the total Nottingham Health Profile scores in both groups indicates that these assumptions cannot easily be made.

It is feasible that the randomisation scores for the Nottingham Health Profile are conservative, as those patients non-responding were clinically worse, demonstrated by a lower Barthel Index score. As a consequence, the comparisons across group scores should proceed with caution. Change data from randomisation to either the three or twelve month assessment point is relatively more robust, as missing data at randomisation prevents further analysis.

The change in Nottingham Health Profile score from three to twelve months is the assessment with the most complete data, and has therefore been taken as the main outcome of interest. Here the mean change in the control group was an improvement of approximately 9 Nottingham Health Profile units, with just over 44 units in the experimental group. In this case, visual inspection of histograms demonstrates a reasonable normal distribution, strengthening the validity of the mean change in each group and the corresponding 95% confidence interval.

Social activities

Engagement in activities of living was assessed using the Frenchay Activities Index at randomisation, and at the three and twelve month assessment points (Table 9.14). The general trend in scores was consistent across both the control and experimental group, with median scores higher at the twelve month as compared to three month assessment point.

The change in Frenchay Activity Index scores from randomisation to the three month assessment period (Table 9.15) demonstrates the significant impact that the consequences of stroke can have in an individual's performance of activities of

living. The performance of activities of living in both groups improved from three to twelve months; this improvement appeared to be slightly more pronounced in the experimental group. Any differences between the groups in terms of improvement were not however statistically significant.

The results indicate that the Frenchay Activity Index is sensitive to the consequences of stroke, indicated by the change in scores from randomisation to the three month assessment period. The general recovery path associated with the current profile of service provision appears to incorporate an element of improvement in activities of living. The study intervention failed to demonstrate any statistically significant improvement in activities of living over and above what improvement may already reasonably be expected.

Depression

Patient depression was assessed using the Beck Depression Inventory at the three and twelve month assessment points (Table 9.16). An explicit assessment of depression using this tool at randomisation was not completed in an attempt to limit the burden of the trial on patients during the early stages of their recovery. Emotional state at randomisation was however assessed in one of the Nottingham Health Profile sub-sections and has already been reported. For the data available at randomisation, both groups were equivalent in terms of emotional reaction as assessed by the Nottingham Health Profile. In addition, pre-existing clinical depression was identified as an exclusion criterion prior to entry into the trial.

Whilst the median score in the control group is higher at the three month assessment point than that of the experimental group, this difference is not statistically significant. A similar profile of scores was obtained at the twelve month assessment point. The change in Beck Depression Inventory scores from the three to twelve month assessment period was equivalent across both groups of patients. The change data is also cross-tabulated in Table 9.17 to enable further comparison.

The incidence of depression in the trial patients was explored using the standard Beck Depression Inventory cut-off points and is detailed in Table 9.18. The table demonstrates that assuming the study intervention has no impact on the incidence of depression, then the number of patients with any depression is 37 and 23 at three and twelve months respectively. For depression described as moderate or severe by Beck, Steer and Brown (1996), then the number of patients is lower at 14 at three months and 8 at twelve months. A chi-square test was carried out to check the distribution of these incidences, and the incidence of all levels of depression was shown to be consistent equivalent across both control and experimental groups.

The data would suggest that patients in the control group did have slightly higher levels of depression at both assessment points after randomisation. Differences were not however statistically significant. Nearly a third of patients in the trial experienced some form of depression as defined by the diagnostic ranges of the Beck Depression Inventory.

Carer strain

The impact of the study intervention on carers' perceptions of stress was assessed using the Caregiver Strain Index. Specifically, an assessment of the potential for the study intervention to enhance the experiences of carers after discharge was required. For this reason an assessment at randomisation was not undertaken. It is likely that in this case the tool would assess other domains whilst patients were in hospital in the immediate aftermath of stroke. Similarly, where patients were resident in a nursing or residential home, this section of the assessment profile was also omitted as patients were in receipt of some form of professional care.

The numbers of carers for whom data is available is smaller than that for patient data, and is detailed in Table 9.19. The table demonstrates that the proportions for whom data was available is similar in both experimental and control group patients. This equivalence was checked using the Chi-square test.

Table 9.20 details the median and interquartile range of Caregiver Strain Index scores at the three month assessment point. Whilst the profile of scores is similar across the two groups, the carers of patients receiving post-discharge support perceived lower degrees of stress than those carers of control group patients. Whilst achieving statistical significance, this difference did not extend to the twelve month assessment point.

Using the median as an indicator of the central tendency of the degree of change from three to twelve months does not easily demonstrate the real change evident in a small number of carers. Change data is therefore cross tabulated to aid

interpretation (Table 9.21). In fact the distribution of the change in caregiver strain index scores on histograms appeared to be near normal, with the mean changes close to zero, and tight 95% confidence intervals (experimental group mean -0.62 ($-1.17, -0.08$); control group mean -0.33 ($-0.89, 0.23$)). This would suggest that caregiver strain index scores are reasonably consistent over time across both the control and experimental group. Whilst statistical significance was reached at the three month assessment phase, the lack of significance at twelve months may be due to two factors:

- poorer long-term effectiveness of the trial intervention in promoting perceptions of coping in carers, or
- the reduced power associated with the smaller numbers of carers providing data at twelve as oppose to three months.

Whilst the individual, or combined effects of these two scenarios may only be postulated, the fact that most patients did not receive the trial intervention after three months would suggest the first explanation is more important.

Sensitivity analyses

The potential for missing data to reduce the validity of a trial findings has been well documented. The distribution of missing data was described earlier in this chapter as being equivalent across both the control and experimental group. For the trial population as a whole, missing data was not associated with any specific characteristics assessed at randomisation.

A decision was taken to focus sensitivity analysis on the consideration of missing data at the twelve month assessment period, where the highest proportion of

missing data was observed, and the change in Nottingham Health Profile data from three to twelve months. The intention of the sensitivity analysis was to assess the validity of the key interpretations of the data.

The first sensitivity analysis involved re-coding all patients who had died by twelve months to extreme values, where this could be argued from a 'clinical' perspective. For those patients who had died, the Barthel Index score was recoded to zero, the Frenchay Activity Index to zero, and the Nottingham Health Profile to 600. Re-coding the Beck Depression Inventory was deemed inappropriate. The difference between the two groups in terms of the total Nottingham Health Profile remained evident (Table 9.22). This analysis was repeated using the revised change in Nottingham Health profile scores from three to twelve months. In this case, the improvements in perceived general health at twelve months in the experimental group persisted (Mann Whitney Test $p=0.021$), as did the improvements in scores from the three to twelve month assessment point (Mann Whitney Test $p=0.057$).

The second sensitivity analysis focused on the substitution of three month scores for the remainder of data missing at twelve months (Table 9.23). No substitution was made if data for the first assessment point was missing. In this sensitivity analysis, the experimental group median continues to demonstrate lower total scores on the Nottingham Health Profile, equivalent to higher levels of perceived general health (Mann Whitney Test $p=0.005$).

In summary, both sensitivity analyses demonstrate that in general the pattern of patient outcome is consistent across both groups of patients. Incorporating all

available data indicates that the perceived general health of both groups of patients improves from the 3 to 12 month assessment points. When accounting for patient mortality, the improvements in control group patients appear to be substantially reduced, whereas those of experimental group patients are consistent. Further, the assumption that those patients for whom data is missing do not experience any change in their perceived health from three to twelve months does not appear to affect the pattern of outcome in the control group. In the experimental group however, perceived general health is slightly reduced. This would suggest that in general, the benefits of the study intervention are consistent when subjected to statistical examination. Some caution is required however in relation to the potential impact of missing data.

Economic analyses

The economic evaluation of the trial intervention was completed in three parts. The first part, focusing on length of stay, was intended to assess the equivalence of baseline costs across the experimental and control group. The distribution of services after discharge from hospital was intended to provide an indication of the equivalence of follow-up costs. Where these issues are demonstrated to be equivalent, then the relative costs of any change in patient or carer outcome can be assessed directly through the trial intervention costs.

The average length of stay for stroke patients varies from trial to trial, but is often between 20 and 25 days. In this trial however the mean length of stay was nearly double (experimental 45 days; control group 49 days) (Table 9.24). The variation

of length of stay between the two groups was not statistically significantly different.

The profile of services received by patients after discharge from hospital are detailed in Table 9.25. The distribution of follow-up services was checked at both three and twelve months and differences between the two groups were found to be non-significant.

The prevalence of readmission to an acute hospital environment for both groups at each assessment point was used as a proxy for readmission costs. The prevalence rate for experimental group patients was calculated as 16% at three months and 6% at twelve months. For control group patients the rates were 17% at three months and 15% at twelve months. Differences in these rates were not shown to be statistically significant, however there is a clinically significant difference at the twelve month assessment point. Here the difference in the admission prevalence rate between the control and experimental group was 9.07% (18.38, 0.24).

It was not possible to separate the costs of delivering the study intervention in terms of both the trial and clinical practice. Proxy costs may therefore be witnessed in the amount of time devoted to the training for, delivery of and management of the trial intervention, including leave and absence. Broadly speaking two days per week were devoted to the trial over nineteen months. The total recorded cost of this time was £16,116. This figure can be contrasted to the relative benefits of the trial intervention: an increase in perceived general health of

just over 7% in a group of 87 patients, when considered against the full range of Nottingham Health Profile scores.

Ancillary analyses

Unplanned ancillary analyses were kept to a minimum in view of the potential threat to the validity of trial findings caused by multiple statistical testing. A number of unplanned comparisons were undertaken to explore between-group equivalence in terms of the presence or absence of data at randomisation. These have been included earlier in this chapter.

The systematic review indicated the potential for targeting similar interventions to subsets of patients to maximise health gain and to assist in service planning. The Forster and Young trial (1996) attempted to do this by focusing on a subset of patients defined according to independence as indicated by Barthel Index scores. An exploration of the potential utility of this post-hoc stratification was completed on the data set for this trial using the General Linear Model function of SPSS to obtain a factorial analysis of variance test. The dependent variable was the change in Nottingham Health Profile scores across the assessment points. Similarly to the Forster and Young (1996) trial, the between-subject factors were identified as randomisation status and randomisation Barthel Index stratification (0-14, 15-20). The F ratios for the factorial analysis of variance tests are detailed in Tables 9.26.

Using the simple stratification of the Barthel Index score at randomisation would appear to confirm the key effects of the intervention after the three month assessment point. Table 9.26 demonstrates that the experimental treatment had a

significant effect on the change in Nottingham Health Profile scores from three to twelve months ($F(1,112) = 4.02$; $p < 0.05$). Any changes in Nottingham Health Profile scores from randomisation to the three month assessment point appeared to be significantly affected by the stratified Barthel Index score at randomisation ($F(1,83) = 5.80$; $p < 0.05$).

Adverse events

No significant adverse events were identified that had the capacity to seriously affect the internal validity of the trial. Where deviations from the protocol were identified, the impact of these incidents in terms of intention-to-treat and data analysis have been clearly identified.

One patient was identified as at risk of suicide at follow-up assessment on the Beck Depression Inventory. The protocol agreed with the Community Psychiatric Nursing team was invoked and no subsequent problems with this patients management were noted.

There were periodic misunderstandings between study stakeholders of the implications of the study, particularly in relation to the management of the practitioner delivering the trial intervention. These issues were identified in the associated studies, and are explored later in this and subsequent chapters.

Acceptability study

A total of six interviews with patients in the experimental group were undertaken. Interviews ranged from 22 minutes to 66 minutes in length, with a mean of 41 minutes. Informal carers were present at three of the interviews. All interviews were undertaken in the patient's home. Whilst some quotes have been included in this chapter to contextualise the findings, the key findings from this exploratory study suggested that the study intervention was generally appreciated by patients and carers.

A key finding from this associated study reflected little understanding of the role from the patient perspective. This is particularly evident in the following quote, which highlights a conflicting account:

"...a great help, but there was nothing that I really needed or wanted.....sometimes I felt like a prisoner in my own home..." (Interview with TRN 106)

Whilst some confusion existed about the role, which is perhaps inevitable, there were consistencies in the data highlighting perceived utility, particularly in the case of the availability of dedicated support.

"...it gave me confidence, knowing help was available..." (Interview with TRN 106)

This particularly appeared to be the case in the immediate period after discharge from hospital

“I just came out. I didn’t know anything about it until the stroke nurse came”

(Interview with TRN 105)

Tangible physical benefits of the trial intervention were identified when delivery included aspects of case management. Where this theme was evident, there seemed scant regard for the processes that were working to implement and deliver the final programme of care or treatment. Where the stroke nurse may actually have been involved in only a referral or negotiating an assessment, any change in circumstances that arose from these actions was seen to be the sole responsibility of the stroke nurse. Patients appeared to have little regard for the intricacies and sensibilities of multidisciplinary care.

“She was the one who got the aids sorted. The chair lifts up. It was very good.”

(Interview with TRN 74)

An important theme in the data did however relate to the ‘fit’ between the trial intervention and the perceived realities that stroke patients appeared to face. Whilst these aspects of the trial intervention are less tangible than in the previous quote, they were nevertheless valued by patients.

“It’s the small things and if there was anything that was really bothering us...We talked about my hip (carer was recovering from a total hip replacement). Nobody had done that before. It did worry me because I was worried how I was going to

cope with him. I'm surprised nobody had picked up on that. It's all water under the bridge. Anyway that was a great help." (Interview with TRN 92)

All patients identified the stroke nurse as being a source of information and advice in the immediate period after discharge. The following quotation is typical, and relates to supporting realistic expectations of recovery.

"The stroke nurse told me it might be up to eighteen months and it is getting a little better already. I hope it carries on." (Interview with TRN 36)

Whilst the data were encouraging, there were clear misunderstandings about the purpose of the trial intervention, and what aspects of recovery from stroke may be addressed by providing continuing nursing case management after discharge from hospital. Patients appeared to be able to identify instances where the intervention was useful, and what it had actually achieved for them in practice. What was striking in the data however was the considerable amount of unmet need that prevailed for patients and carers who took part in this part of the study.

Intervention intensity study

The mean number of interactions between the stroke nurse and patients in the trial was three. Five patients did not receive the study intervention due to staff absence. Due to the intention-to-treat strategy, these were included in the analysis of outcome data. The full distribution of the frequency of contact episodes amongst the experimental group patients is detailed in Figure 9.2.

Most of the intervention was delivered in the first month after discharge from hospital. Few patients maintained contact with the stroke nurse after four months. The distribution of the duration of the study intervention is detailed in Figure 9.3.

An assessment of the association between the intensity of the trial intervention and patient outcomes was specified *a priori* in the Trial Analysis Plan. Specifically the relationship between the number of contact episodes between the patient and stroke nurse, and the duration over which these episodes occurred were explored using the Spearman rank correlation.

Spearman rank correlation coefficients demonstrate that, as expected, the association between the number of contact episodes and the length of time over which these episodes occur is strong (Tables 9.27). No clinically or statistically significant relationships between these two factors and changes in the Nottingham Health Profile total score from the three to twelve month assessment points were detected. The clinical implications of correlation in this trial are complex and contradictory. For example, the quantity and duration of interaction between patients and the trial intervention may have been increased in response to poor outcome. In an attempt to address this issue, the change in Nottingham Health Profile score was stratified to a binary variable, representing either an increase or decrease in perceived general health. No statistically significant relationships between this new variable, the duration of intervention and the number of contact episode were identified.

In the investigation of trial documentation, data were also obtained on the subtypes of intervention that was provided to patients in the trial. For each patient in

the experimental group, documentation was reviewed and each explicit interaction noted. These interactions were coded according to the classification described in Chapter Four: care provision, care management and therapeutic nursing.

Care giving

The least frequent mode of interaction was care giving, which included activities designed to

- provide direct care
- ensure completion of regimes prescribed by others, and
- to prevent harm

In this mode, the most frequent activity focused on the management of medication.

Appointment made for follow-up as not taking bendrofluazide. Discussed with (GP) who will monitor blood pressure. (Record for TRN 99)

TTO checked and discussed with pharmacy – dispensed wrongly should be 10mg not 5mg. Message left for GP re dosage. (Record for TRN 112)

GP has prescribed movicol. Called out to discuss bowels. (Record for TRN 17)

Bar chart of the frequency of contact between patients and stroke nurse.

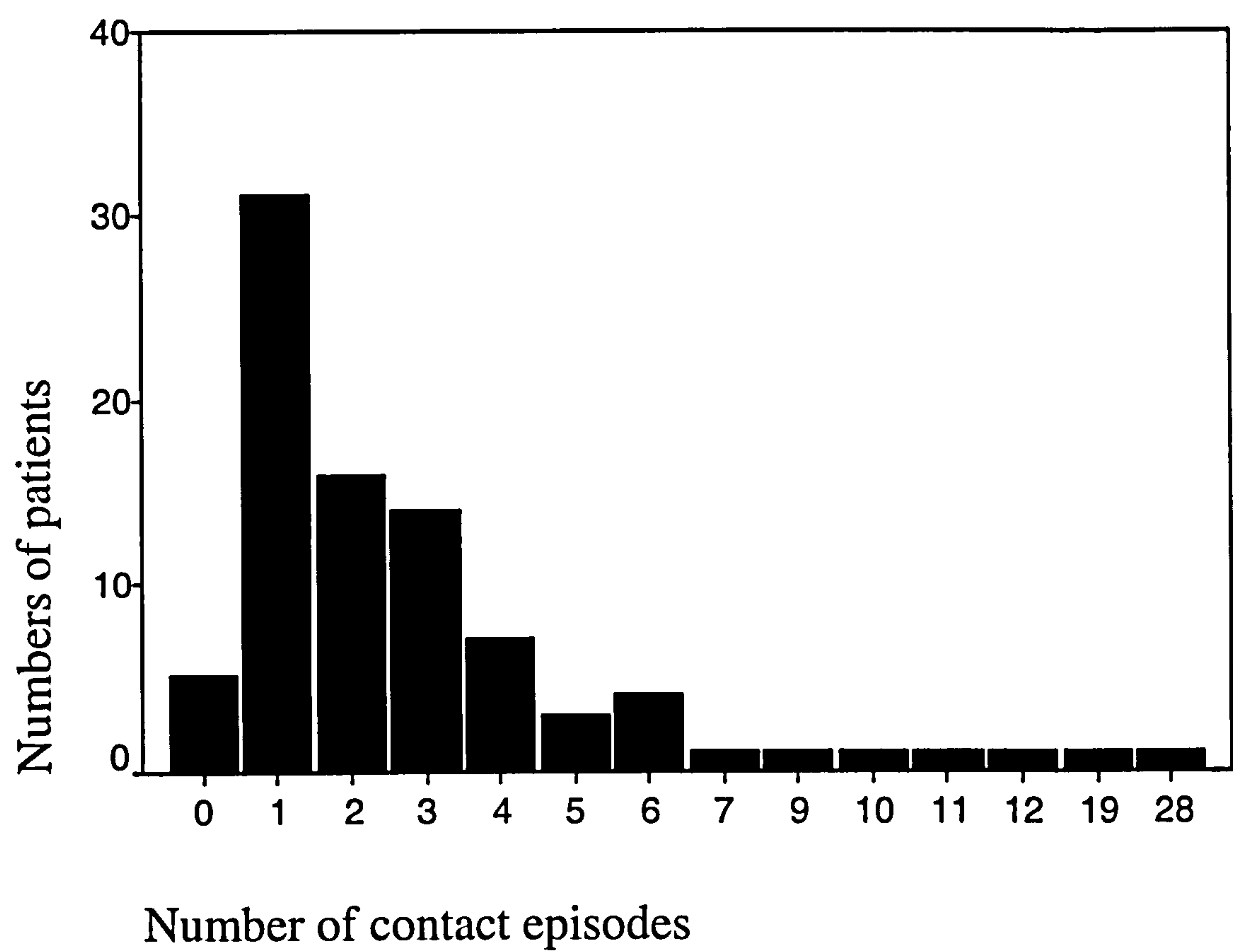


Figure 9.2

Bar chart of the duration of the study intervention

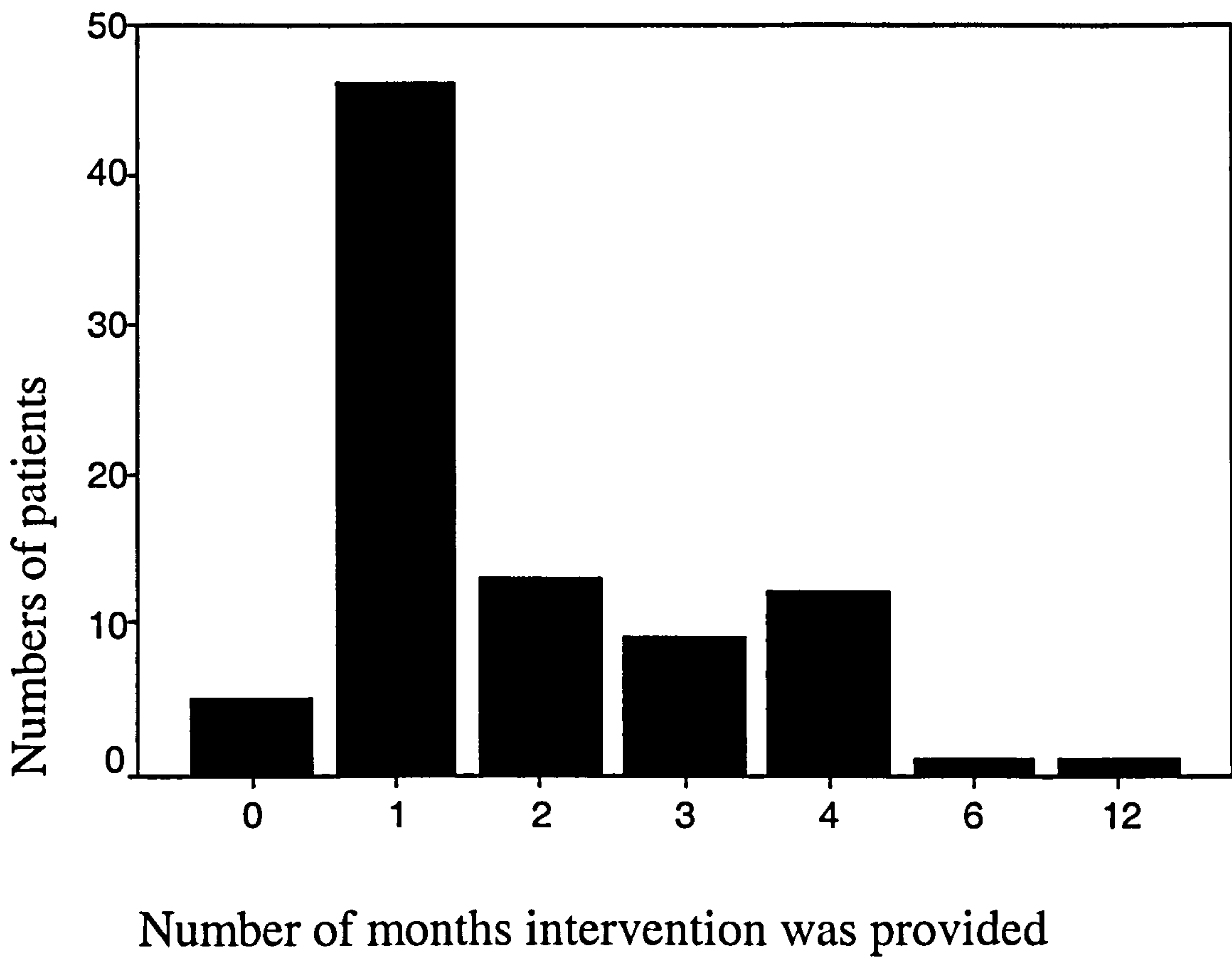


Figure 9.3

Direct care almost never related to activities other than checking vital signs, such as blood pressure, in the event of patients appearing to be physically unwell.

Phone GP and symptoms explained. He will visit later today. (Patient) refusing to allow me to inform his daughter but eventually would let me phone his friend to stay with him until GP arrived. Admitted to (hospital). (Record for TRN 3)

Contribution to the management of hypertension tended to be limited to discussions with patients' general practitioners.

Care management

The next mode of interaction focused clearly on activities relation to care management, with a focus on co-ordinating professional input across health care boundaries and sectors.

Fasting lipid results discussed with (consultant). Needs dietician referral. Letters sent to GP and dietician. (Record for TRN 105)

Discussed with (therapy manager) who will chase up day hospital appointment. (Record for TRN 33)

A considerable number of activities in this mode involved communication with other health care professionals for referrals, modifications to rehabilitation plans, and confirming or amending appointments.

Discussed problem with physiotherapist who will assess this week for rotator frame. (Record for TRN 74)

Discussed situation with ophthalmic department – can do a referral letter to (consultant) and they will inform me if needed. (Record for TRN 80)

The nurse as therapeutic practitioner

The most significant mode of interaction focused on activities designed to promote recovery in its widest sense. At a theoretical level this mode included activities designed to:

- maintain and improve emotional and social well-being
- enhance coping strategies
- improve performance of meaningful activities of living.

At a practical level this mode of interaction could be witnessed in documented discussions with patients and carers about levels of physical activity such as shopping or leisure activities, health promotion, socialisation and family networks, and emotional issues.

Desperately wanting to walk out into garden. Walked with me, much more steady. Suggested sitting at the sink to do washing up. (Record for TRN 167)

Discussed with (GP) re: depression. Already on small dose of dothiepin and he will increase. (Record for TRN 75)

Encouraged to continue with piano. (Record for TRN 92)

Discussed amitryptilline with GP. Community OT also feels he has sensory nerve problems as has good movement range but pain restricting movement. GP agreed to try amitryptilline 25mg nocte. (Record for TRN 103)

Not managing to help (wife) with shopping. Causing emotional upset. Discussed what aspects of shopping they could do together. (Record for TRN 74)

Some problems evident with looking after (grandchild). Discussed some ways of coping with him, including reducing the number of times they look after him. (record for TRN 106)

Practice context of the study intervention

The stroke nurse was required to record all patient and carer interaction delivered as part of the trial intervention in a specially designed document. In addition, critical reflection records (n=12) and interviews (n=3) were also used to record contextual issues that shaped the implementation of the trial intervention.

A total of twelve critical incidents were completed, ten labelled positive and two labelled negative by the stroke nurse. The negative critical incidents related to

- inability to deal with anti-social behaviour exhibited by one patient, and
- inability of a patient to contact the stroke nurse after a phone number switch.

Both issues were reported to have been resolved with little difficulty.

The positive critical incidents related either to identifying and addressing unmet patient or carer needs, correcting errors as for example in prescriptions and ironing out problems in the communication of follow-up services. One positive critical incident related to dealing with a medical emergency during a home visit. Whilst the lessons learned from each incident were different, one key factor was identified in each incident as being integral to successful resolution. This was 'knowing how the system worked' and being able to readily identify and contact the most suitable resource.

The interviews were conducted away from the research site at regular intervals throughout the trial. Three individuals participated in the interviews which were structured as a group discussion. These were the investigator, the stroke nurse and a nurse academic with expertise in the advancement of nursing practice. The interviews were semi-structured, and focused on the following three themes:

- aims of clinical practice
- values and assumptions underpinning clinical practice
- the power relationships reflected in values and assumptions.

Each interview lasted for between one half and three quarters of an hour. The broad themes in the data are presented

Aims of clinical practice

The stated aims of the stroke nurse in providing the study intervention related principally to the notion of a whole case, acting as a resource for staff and patients.

“Its very much like acting as case manager. Continuing that case management through into the community.” (Interview 1)

“...now come to see me more as a case manager...” (Interview 2)

Perhaps inevitably, there was a focus on an holistic and long-term approach to the consequences of stroke, which in turn centred on the problems and needs identified by individual patients.

*“...It’s about how much they want to progress and where they want to go to...”
(Interview 1)*

“...visualise a future...” (Interview 1)

*“...thinks I’m there to sort out every stroke problem would be it in a nutshell. And for things that... can’t sort out ...sees me there to give guidance about how to progress or how to learn to live with the bit that has got to be lived with.”
(Interview 1)*

The ability to communicate openly with patients and carers was seen as important to the adoption of an holistic approach. The emphasis on communication appeared to be a two-way dialogue between patient and stroke nurse, rather than purely the transmission of information.

*“I have more time to sit down and talk with her and develop a rapport with her.”
(Interview 1)*

Values and assumptions

There appeared to be an underlying belief that current approaches to clinical practice were limited in their applicability.

“It made me realise how little preparation we do for people going out into the community. We don’t look at the socialisation. It’s the reality.” (Interview 1)

There was also a belief that hospitalisation itself could produce negative effects for patients.

“It’s very different for patients at home. They don’t seem to be institutionalised...you know accepting things being done to them rather than with them...and I see my role as really to empower them while they are in hospital so that they are in control when they go home...” (Interview 3)

This criticism appeared to be translated in a critical stance on the accepted priorities for care and treatment, with an increased focus on patient priorities.

“It makes you wonder what are patients priorities.” (Interview 1)

Whilst emphasis was made of individuality in planning ongoing care, the importance of progress appeared to remain a high priority for the stroke nurse. This was markedly the case for one patient who displayed low motivation for recovery.

“...he’s saying that yes he would like to go out and be able to do the banking again and then in another phrase he’s saying well (wife) can do it...” (Interview 2)

Here the stroke nurse discussed the utility of continuing to provide input with some degree of uncertainty. Whilst her interpretation of the situation focused on the degree of recovery that the patient wanted, it was not however necessarily easy to accept this as a valid outcome of intervention. Focusing on this issue elicited a forceful rejection of pre-planned aims:

“No, I never go in with an aim. I never go in with it. I see what develops through a relationship and change what develops over time” (Interview 2)

Power relationships

Advocating two-way communication was mirrored in the perception of the relationship between the stroke nurse and the patient and carer, which was often seen as iterative.

“It was very much getting to know her as a person, and her getting to know me as a person.” (Interview 1)

“You’ve got to develop with them.” (Interview 2)

There was a general perception that patients did not, or were not able to, adopt a more proactive role in contributing to individual rehabilitation plans.

“They will take quite often what a professional says as being hard and fast and just follow it to the full stop.” (Interview 2)

Perhaps inevitably with the implementation of a new clinical development, establishing the trial intervention into the bedrock of everyday practice was problematic. Whilst the incidence of problems was in fact small, where they did occur often related to misunderstandings about the boundaries of clinical practice.

“...if your role is something new and different you’ve got to be prepared to stick your neck out a little bit.” (Interview 2)

“...the (therapist) that went out wasn’t best pleased because...saw the care plan and saw that (patient) had been going up and down the stairs”. (Interview 2)

Management support was seen to be essential to the success of the trial intervention in practice, particularly in dealing with multidisciplinary issues. As such, relationships with managers often involved a degree of negotiation and compromise.

“I’ve learned the priorities of my manager” (Interview 2)

“I could really have benefited from the power to be flexible to respond to the needs of patients. In the future I would say that power is essential” (Interview 3)

A key difficulty at times related to what were perceived to be competing demands on the stroke nurse role, both in continuing the baseline or usual level of service together with the trial intervention.

“...two very different management demands. It felt like being a pig in the middle. It was very difficult to please both sets...I feel that as the workload increased then it all got worse. Being told what to do didn’t empower me...” (Interview 3)

Taking on responsibility for maintaining the current stroke nurse role, together with delivery of the trial intervention inevitably introduced an artificial split into the role. This appeared to be where competing demands were located, particularly when authority to fulfil both aspects of the role rested in different management teams. This precipitated perceptions of helplessness and a lack of commitment to the role from others. The need to establish management boundaries for the development of this type of service development was clearly identified. Communication was seen as the critical issue in determining the success of the trial intervention, and was sighted as the principal factor in precipitating both positive and negative critical incidents. The benefits of ensuring professional staff were aware of the trial intervention was summed up:

“One of the other things as well that we did, which I haven’t mentioned, and which has helped is that I did a session in the day hospital about what my role was...” (Interview 2)

A lack of shared meaning of the trial intervention was not however restricted to relationships with other members of the multidisciplinary team and management. Patients and carers were often unaware of what could be expected or offered as part of the trial intervention.

“Its more about his bowels and his water works, which is maybe how they see my role. Maybe I’ve not put my role across well enough. I don’t know.” (Interview 2)

Pilot work on the implementation of the trial intervention had focused on the identification of community based resources, and access to these resources appeared to be helpful. The availability of staff to discuss issues relating to individual patients in the community appeared to be reduced as compared to the hospital environment.

“...the GPs have all been extremely positive and helpful. But it still isn’t as easy to discuss issues out in the community.” (Interview 3)

Whilst identifying the positive contributions of the majority of health care professionals in the community to the successful implementation of the trial intervention, the pilot work to identify community and hospital resources appeared to be particularly important.

“...knowing how the systems worked. You know who to ring to get things done... and knowing who would in fact do them...That has probably got to be the most important thing in doing this type of work.” (Interview 3)

Chapter summary

This is a lengthy and complex chapter which reports the key findings of one main study, and three associated studies. The findings would suggest that the intervention has some ability to promote a greater sense of emotional and social wellbeing as indicated in traditional outcome measures. The exact nature and origins of this improvement is difficult to ascertain, as it is not located in any of the measured aspects of intervention intensity. The importance of addressing long-term recovery needs advocated by patients and carers, coupled with the articulated focus of the trial intervention would suggest that this may be an area for increased attention. Delivering this type of intervention is however difficult in a clinical organisation, as it is located at the traditional boundaries of multiprofessional practice. These issues will be further explored in the next chapter, by relating the findings of this trial to the wider evidence-base, uncovered in earlier chapters of this thesis.

Presentation of Qualitative Data	
Examples of data sources	Presentation format
Clinical records maintained for patient with the Trial Registration Number 33	<i>Record for TRN 33</i>
Second interview with Stroke Nurse	<i>Interview 2</i>
In-depth interview with patient in the experimental group with Trial Registration Number 33	<i>Interview with TRN 33</i>

Table 9.1. The presentation of data

	Experimental (n=87)	Control (n=89)
Male Sex	47 (54.0%)	45 (50.6%)
Admitted with first stroke	63 (72.4%)	63 (70.8%)
Admitted to Hospital A	49 (56.3%)	49 (55.1%)
Discharged Home	69 (79.3%)	69 (77.5%)

Table 9.2. Distribution of baseline variables

Distribution of Age by Group Allocation (mean and standard deviation in years)	
Control (n=89)	Experimental (n=87)
74.7 (10.5)	75.8 (9.6)

Table 9.3. Distribution of patient age.

	Nottingham Health Profile at Randomisation		Frenchay Activity Index at Randomisation	
	Completed	Incomplete	Completed	Incomplete
Control (n=89)	44 (49.4%)	45 (50.6%)	49 (55.1%)	40 (44.9%)
Experimental (n=87)	43 (49.4%)	44 (50.6%)	49 (56.3%)	38 (43.7%)

Table 9.4. Distribution of Nottingham Health Profile and Frenchay Activity Index assessments at randomisation.

	Score at Randomisation (median and range)	
	Control	Experimental
Barthel Index score	13 (0, 20) (n=89)	13 (2, 20) (n=87)
Frenchay Activity Index score	28 (6, 44) (n=49)	24 (6, 43) (n=49)

Table 9.5. Distribution of Barthel and Frenchay Activity Index scores at randomisation.

Nottingham Health Profile Score at Randomisation (median and range)		
	Control (n=44)	Experimental (n=43)
NHP (Energy)	39.20 (0, 100)	39.20 (0, 100)
NHP (Emotional Reaction)	28.35 (0, 100)	36.62 (0, 100)
NHP (Physical Mobility)	52.41 (0, 100)	42.20 (0, 100)
NHP (Pain)	10.61 (0, 100)	0.00 (0, 53.86)
NHP (Social Isolation)	22.27 (0, 100)	20.13 (0, 100)
NHP (Sleep)	21.70 (0, 100)	21.70 (0, 100)
NHP (Total Score)	202.89 (43.63, 419.32)	209.97 (0, 426.79)

Table 9.6. Distribution of Nottingham Health Profile scores at randomisation.

Barthel Index score (median and range)			
	Randomisation	3 months	12 months
Control	13 (0, 20) (n=89)	14 (1, 20) (n=89)	13.5 (2, 20) (n=62)
Experimental	13 (2, 20) (n=87)	15 (1, 20) (n=87)	17 (1, 20) (n=63)

Table 9.7. Assessment data for the Barthel Index

Changes in Barthel Index score (median and range)			
	Randomisation to 3 months	3 to 12 months	Randomisation to 12 months
Control	0 (-18, 13) (n=89)	0.0 (-4, 8) (n=62)	-1.0 (-10, 13) (n=62)
Experimental	0 (-12, 14) (n=87)	0.0 (-2, 5) ¹ (n=63)	1.0 (-10, 14) (n=63)

¹Mann Whitney Test p=0.049

Table 9.8. Changes in Barthel Index scores

Change in Barthel Index Scores (Randomisation to 3 months)							
	≥-5	-4 to -3	-1 to -2	0	+1 to +2	+3 to +4	≥+5
Control (n=89)	6	7	22	16	11	12	15
Experimental (n=87)	9	9	12	17	15	9	16

Table 9.9.1. Distribution of change in Barthel Index scores from Randomisation to 3 months.

Change in Barthel Index scores (3 to 12 months) ¹							
	≥-5	-4 to -3	-1 to -2	0	+1 to +2	+3 to +4	≥+5
Control (n=62)	0	3	25	21	8	3	2
Experimental (n=63)	0	0	17	28	14	3	1

¹Mann Whitney Test p=0.049

Table 9.9.2. Distribution of change in Barthel Index scores from 3 to 12 months.

Change in Barthel Index scores (Randomisation to 12 months)							
	≥-5	-4 to -3	-1 to -2	0	+1 to +2	+3 to +4	≥+5
Control (n=62)	5	7	17	7	11	4	11
Experimental (n=63)	6	5	6	14	13	7	12

Table 9.9.3. Distribution of change in Barthel Index scores from Randomisation to 12 months.

Nottingham Health Profile score at 3 months (median and range)		
	Control (n=83)	Experimental (n=82)
NHP (Energy)	39.20 (0, 100)	24.00 (0, 100)
NHP (Emotional Reaction)	40.91 (0, 100)	24.46 (0, 100) ¹
NHP (Physical Mobility)	54.55 (0, 100)	54.55 (0, 100)
NHP (Pain)	11.22 (0, 100)	5.83 (0, 100) ²
NHP (Social Isolation)	30.52 (0,100)	22.01 (0, 100) ³
NHP (Sleep)	12.57 (0, 100)	12.57 (0, 100)
NHP (Total Score)	194.30 (12.57, 522.12)	161.54 (0, 515.67)
¹ Mann Whitney Test p=0.01 ² Mann Whitney Test p=0.056 ³ Mann Whitney Test p=0.013		

Table 9.10. 3 month assessment data for Nottingham Health Profile.

Nottingham Health Profile score at 12 months (median and range)		
	Control (n=57)	Experimental (n=61)
NHP (Energy)	24.00 (0, 100)	24.00 (0, 100)
NHP (Emotional Reaction)	34.22 (0, 100)	19.78 (0, 100) ¹
NHP (Physical Mobility)	54.47 (0, 100)	45.19 (0, 100)
NHP (Pain)	11.22 (0, 100)	5.83 (0, 79.14)
NHP (Social Isolation)	38.50 (0, 100)	15.97 (0, 100) ²
NHP (Sleep)	12.57 (0, 100)	12.57 (0, 100)
NHP (Total Score)	177.51 (11.22, 528.61)	134.86 (0, 506.85) ³

¹Mann Whitney Test p=0.037 ²Mann Whitney Test p=0.002 ³Mann Whitney Test p=0.012

Table 9.11. 12 month assessment data for the Nottingham Health Profile.

Change in Nottingham Health Profile score (median and range)		
	Control	Experimental
Randomisation to 3 months	3.37 (-138.00, 245.51) (n=44)	-0.38 (-265.93, 245.51) (n=43)
3 months to 12 months	-11.32 (-308.07, 251.92) (n=56)	-29.29 (-308.07, 251.92) ¹ (n=60)

¹Mann Whitney Test p=0.039

Table 9.12. Change in the Nottingham Health Profile scores from Randomisation to 3 months.

Nottingham Health Profile Total scores (mean and 95% confidence interval)		
	Control	Experimental
3 months	229.47 (200.34, 258.60) (n=83)	187.43 (160.21, 214.65) ¹ (n=82)
12 months	218.94 (185.14, 252.73) (n=57)	158.36 (129.21, 187.51) ² (n=61)
Change in Score from 3 to 12 months	-8.81 (-34.36, 16.75) (n=56)	-44.37 (-69.10, -19.63) ³ (n=60)

¹T Test p=0.037 ²T Test p=0.007 ³T Test p=0.048

Table 9.13. Mean and 95% Confidence Intervals for the Nottingham Health Profile total scores.

Frenchay Activity Index (median and range)			
	Randomisation	3 months	12 months
Control	28 (6, 44) (n=49)	7 (0, 34) (n=85)	12 (2, 34) (n=58)
Experimental	24 (6, 43) (n=49)	7 (0, 39) (n=84)	14 (0, 38) (n=62)

Table 9.14. Assessment data for the Frenchay Activity Index.

Change in Frenchay Activity Index score (median and range)		
	Control	Experimental
Randomisation to 3 months	-15 (-26, 8) (n=49)	-14 (-39, 8) (n=49)
3 months to 12 months	2 (-10, 18) (n=58)	4 -(7, 18) (n=61)

Table 9.15. Change in Frenchay Activity Index scores from 3 to 12 months.

Beck Depression Inventory scores (median and range)		
	Control	Experimental
3 months	11 (2, 36) (n=81)	9 (0, 36) (n=80)
12 months	10 (3, 31) (n=56)	8 (1, 28) (n=61)
Change in Score from 3 to 12 months	-1 (-9, 10) (n=55)	-2 (-11, 18) (n=59)

Table 9.16. Assessment data for the Beck Depression Inventory.

Change in Beck Depression Inventory scores (3 months to 12 months)							
	≥-5	-4 to -3	-1 to -2	0	+1 to +2	+3 to +4	≥+5
Control (n=55)	5	7	18	8	9	3	5
Experimental (n=59)	10	9	20	8	8	2	2

Table 9.17. Distribution of change in Beck Depression Inventory scores from Randomisation to 3 months.

Beck Depression Inventory range	3 month assessment		12 month assessment	
	Control (n=81)	Experimental (n=80)	Control (n=56)	Experimental (n=61)
Minimal	59 (72.8%)	65 (81.3%)	44 (78.6%)	50 (82.0%)
Mild	14 (17.3%)	9 (11.2%)	7 (12.5%)	8 (13.1%)
Moderate	6 (7.4%)	4 (5.0%)	4 (7.1%)	3 (4.9%)
Severe	2 (2.5%)	2 (2.5%)	1 (1.8%)	0 (0.0%)

Table 9.18. Incidence of severity of depression at 3 and 12 months by randomisation status

	3 month data available		12 month data available	
	Yes	No	Yes	No
Experimental	55	32	37	50
Control	56	33	36	53

Table 9.19. Completion of the Caregiver Strain Index

Carer Strain Index scores (median and range)		
	Control	Experimental
3 months	6 (0, 10) (n=56)	4 (0, 12) ¹ (n=55)
12 months	5.5 (0, 9) (n=36)	4 (0, 10) (n=37)
Change in Score from 3 to 12 months	0 (-5, 3) (n=36)	0 (-4, 3) (n=37)

¹Mann Whitney Test p=0.045

Table 9.20. Assessment data for the Carer Strain Index.

Change in Carer Strain Index scores (3 months to 12 months)							
	≥-5	-4 to -3	-1 to -2	0	+1 to +2	+3 to +4	≥+5
Control (n=36)	1	3	9	11	11	1	0
Experimental (n=37)	0	5	12	11	8	1	0

Table 9.21. Distribution of change in carer Strain Index scores from 3 months to 12 months.

Deaths recoded to extreme scores	Scores at 12 months (median and range)	
	Control	Experimental
NHP (Total)	226.78 (264.70) (n=65)	162.15 (161.90) ¹ (n=68)
Change in NHP from 3 to 12 months	0.61 (115.02) (n=63)	-25.89 (89.73) ² (n=66)
Barthel Index	13.0 (9.0) (n=68)	15.0 (12.0) (n=70)
Frenchay Activity Index	10.0 (18.5) (n=66)	13.0 (15.5) (n=69)
¹ Mann Whitney Test p<0.021 ² Mann Whitney Test p=0.057		

Table 9.22. Sensitivity Analysis – Death recoded to extreme scores

Missing scores recoded to last value	Scores at 12 months (median and range)	
	Control	Experimental
NHP (Total)	195.75 (230.23) (n=81)	144.31 (153.65) ¹ (n=81)
Change in NHP from 3 to 12 months	0.0 (83.43) (n=81)	9.76 (66.77) ² (n=81)
Barthel Index	15.0 (8.5) (n=81)	16.0 (11.0) (n=81)
Frenchay Activity Index	9.0 (15.0) (n=81)	12.0 (14.0) (n=81)
Beck Depression Inventory	10.0 (7.0) (n=81)	8.0 (6.5) (n=81)
¹ Mann Whitney Test p=0.005 ² Mann Whitney Test p=0.005		

Table 9.23. Sensitivity Analysis – Missing data recoded to 3 month assessment

Distribution of Length of Stay by Group Allocation (mean and standard deviation in days)	
Control (n=87)	Experimental (n=84)
48.8 (36.6)	44.7 (38.1)

Table 9.24. Variation in length of stay.

Follow-up services	3 month assessment		12 month assessment	
	Control (n=89)	Experimental (n=86)	Control (n=58)	Experimental (n=62)
No services	28 (31%)	29 (34%)	25 (43%)	28 (45%)
Home-based services only	13 (15%)	10 (11%)	20 (34%)	15 (24%)
Day hospital services only	13 (15%)	16 (19%)	4 (7%)	4 (7%)
Combined services	16 (18%)	15 (17%)	1 (2%)	2 (3%)
In institutional care setting	19 (21%)	16 (19%)	8 (14%)	13 (21%)

Table 9.25. Distribution of follow-up services after discharge from hospital

Nottingham Health Profile score	Intervention group (F Value)	Barthel Index stratum (F Value)	Interaction (F Value)
Randomisation to 3 months	0.61	5.80 ¹	1.63
3 to 12 months	4.02 ²	0.10	0.19

¹p=0.018 ²p=0.047

**Table 9.26. Factorial ANOVA model of Nottingham Health Profile Scores
with Randomisation status and stratified
Barthel Index randomisation score as fixed factors**

Spearman correlation coefficients			
	Change in NHP score from 3 to 12 months	Contact episodes	Duration
Change in NHP score from 3 to 12 months		-0.07	-0.06
Contact episodes	-0.07		0.84 ¹
Duration	-0.06	0.84 ¹	

¹p<0.01

Table 9.27. Spearman correlation coefficients for intervention intensity and change in NHP scores from 3 to 12 months.

Chapter 10

Discussion and Recommendations

Introduction to the chapter

This chapter will present a critical appraisal of both the internal and external validity of the study. Initially, the appraisal will focus on the performance of the study in the clinical setting and the implementation of study methods. This section of the chapter will focus principally on the experimental evaluation of the study intervention. The external validity of the study will be explored in two ways: by the integration of findings from the associated studies within the programme as a whole, and with reference to the relevant evidence-base. The chapter will conclude with an analysis of the implications of the study findings for health care policy, clinical practice and research.

Funding

A key issue for consideration is the effect of funding for this study, which was designed as a pilot to inform the development of future research. Funding was provided for only one individual to implement the study intervention. Although most hospitals will employ only one stroke nurse who has the opportunity to work across health care boundaries, this inevitably will have an effect on the generalisability of study findings. This aspect of the study design was addressed in two ways

- the specification of a minimum level of intervention to ensure consistency across patients in the trial, and
- the incorporation of associated studies of acceptability, intensity and context.

It was hoped that if the intervention did demonstrate clinical effectiveness, then these studies could be used to highlight those aspects of the intervention context and performance that were beneficial.

Population

The study population was obtained by recruiting patients at district general hospitals rather than tertiary referral centres, which enhances the generalisability of study findings. Nearly 90% of stroke patients tend to be admitted initially to an acute medical area, with most receiving rehabilitation in another care setting (Stroke Association, 1999). In this respect the pattern of services available to patients in the trial were representative of the national norm. Nationally it would appear that nearly equal proportions of patients are transferred to stroke units as opposed to general rehabilitation wards. In this study patients only had the opportunity of transfer to one of two general rather than specialist rehabilitation units. Whilst systems were in place in both units to deliver a specialist service, for example multidisciplinary case conferencing, the relative merits of specialist rather than generalist stroke services are well understood (Stroke Unit Trialists Collaboration, 2002). This aspect of stroke care is now recognised and reinforced in national health care policy (Department of Health, 2001a).

The inclusion criteria for the trial did not specifically require confirmation of stroke by computerised topography (CT) scan, and it may be possible therefore that some diagnoses may be suspect. Additionally, whilst data was not routinely collected on CT scanning, it was evident in the review of patient documentation that not all patients received a CT scan during their hospital stay. The inclusion

criteria for this study referred to a working diagnosis of stroke using the World Health Organisation (1971) standard. Whilst all patients included in the trial will have been assessed using this standard, CT confirmation may have subsequently excluded a number of patients. It is unlikely however that this proportion would affect conclusions.

The stated aims of the trial intervention were principally focused to psychosocial concerns. This is reflected in the development of the framework for therapeutic nursing in stroke rehabilitation, and the profile of outcome assessment tools used in the trial. Only limited information on the physical, bio-medical features of the disease were therefore collected by the Barthel Index during the trial. It has been advocated however that where the rate of disability change is a key outcome in an evaluative study, the type of stroke, and in particular whether the stroke is a lacunar or total anterior infarction, should be used as key stratification variable (McNaughton, Weatherall, Taylor *et al*, 2001), as these types of strokes would appear to have the most significant ability to influence rate of disability change. Including this in the design of an evaluation research study would have considerable consequences for the use of scanning resources, and the timely interpretation of scans in clinical practice. Neither of the two studies identified in the systematic review included in-depth information on the type of stroke that patients had suffered. Forster and Young (1996) do however provide information on the side of hemiplegia where appropriate, although this is not explored in any depth in their analysis of data. In any case, the issue of patient diagnosis relates principally to generalisability rather than any potential link between disease, intervention and outcome at the causative level. The intervention was principally focused to the concerns of patients with essentially complex consequences of

disease. It may therefore be worth considering whether this approach to the nursing management of stroke has benefit for other patient populations.

The profile of patients included in the trial was similar to those participating in the two trials identified in the systematic review, with slightly more males than females. The proportion of males in this trial was 52%, compared with 53% in the Forster and Young (1996) trial and 56% in the Folden (1993) study. The average age was also comparable with a mean of 75 years in this trial, compared with a median of 73 years in the Forster and Young trial and a mean of 75 years in the Folden study. Whilst patients with previous stroke were excluded from the Folden study, the proportion of patients with a further stroke included in this study was double that of the Forster and Young study (28% and 14% respectively). Similarly patients in this study were more physically dependent than those participating in the Forster and Young study. The benefits demonstrated in this study may therefore be placed in the context of a potentially more demanding population, with relatively more challenges for recovery.

Experimental intervention

The trial intervention was located within a framework for therapeutic nursing in stroke rehabilitation. Whilst many have advocated the notion of a therapeutic contribution to the nursing care of people with stroke, there is limited empirical evidence to support this. The key purpose of this thesis has been to construct a framework for therapeutic nursing in stroke rehabilitation from nursing theory, and explore its implementation in clinical practice. Kirkevold (1992) proposed that the therapeutic function includes maintenance, interpretation of the

consequences of stroke, consoling and the integration or translation of therapy. Burton (2000c) however focused on the identification of a range of nursing interventions, predominantly educative and supportive, that were focused on the achievement of specific patient outcomes, including coping and adaptation to the consequences of stroke.

This work has been developed within this thesis to construct a formal framework for therapeutic nursing practice in stroke rehabilitation. The framework was explored in a systematic review of relevant research, which demonstrated that this aspect of nursing care was poorly researched. The framework was used to underpin the development of a new therapeutic nursing intervention which was then implemented into clinical practice. Implementation required a balance to be struck between the need for flexibility in clinical practice to respond to individual patient need, with the requirements for a rigorous and generalisable evaluation.

The trial intervention incorporated continuous patient management and rehabilitation from acute patient care and beyond by a stroke nurse, and consequently built on the clinical input the patient and carer received during an in-patient stay. The stroke nurse had a special focus on the provision of therapeutic nursing care to promote long-term recovery, building on the supportive, therapeutic relationships that can develop between the stroke nurse and patient during their hospital stay.

The continued performance of the trial intervention in this case was flexible. This is in stark contrast to the explicit specification of similar interventions, a key component of other related study methods, such as the explanatory trial (Schwartz

and Lellouch, 1967). Whilst explicit and rigid description of trial intervention may have the capacity to enhance the internal validity of study findings, its uncritical application to this pragmatic trial would have been problematic for two reasons:

- The theoretical work underpinning the trial intervention demonstrates the need for flexibility in adopting a patient-led approach to care management
- The pressures of clinical practice may mean that, in reality, which is after all the desired context of a pragmatic clinical trial, any intervention is likely to be subjected to some degree of modification dependent on the prevailing attitudes and resources.

The experimental intervention was described in terms of a minimum requirement for follow-up within two working days. The adoption of an intention to treat approach to the analysis of data meant however that, where this standard was not reached, experimental group data was included in the analysis.

The growth of pragmatism in health services research has precipitated the development of evaluation research methodologies which support the rigorous testing of complex interventions. The major emphasis of this type of evaluation is the testing of the 'whole' intervention, rather than its discreet constituent parts. In this respect it is ideally suited to stroke rehabilitation research, where interventions are rarely uni-disciplinary, or the context of concomitant care is extremely variable. The use of a pragmatic approach to the design and execution of this clinical trial may enhance its ability to demonstrate the relative merits of the stroke nurse intervention in the realities of the clinical arena.

The examination of intervention intensity is particularly useful in circumstances where the delivery of the intervention can be tightly controlled, and dosage

determined a priori. Where this degree of control cannot be achieved, as in the case of a complex intervention delivered flexibly, then the ability to determine the context, strength and direction of any link between intervention and outcome is significantly reduced. Although this study included an attempt to investigate whether a relationship between intervention intensity and the direction of change in individual patient outcome, it added little to understanding the context of the demonstrated effectiveness of the study intervention. The MRC (2000) guidance on the evaluation of complex interventions suggests that these relationships are best explored in the developmental stages of intervention development, usually through the use of observational designs. This is an aspect of the intervention that requires further attention.

The research identified in the systematic review included a guided decision-making intervention, the content of which was clearly defined (Folden, 1993). Here the intervention was underpinned by a nursing theory which promoted the use of interventions designed to facilitate the development of self-care skills in patients. As such it was geared to the process of decision-making in patients, where the nursing role was essentially facilitative. Indeed it is not self-evident in the paper what unique knowledge and skills nurses could bring to enhance the effectiveness of this activity.

Forster and Young's (1996) trial however referred to an intervention which was flexibly delivered, enabling a response to the specific needs of individual patients. Here the emphasis was on the provision of information and advice, with evidence of goal-setting for future recovery. An implicit assumption was made that this was the most appropriate approach to use in the design of interventions to improve the

long-term recovery of patients and carers. This study however included extensive preparatory work, with reference to both nursing theory and theories of recovery from stroke, to ensure that the study intervention had a strong theoretical base. This is particularly crucial in the evaluation of a complex intervention, as it establishes a benchmark for, and consequently strengthens, the proposition of explanations for the pattern of results across the full range of outcome domains included in the study.

Assessment

Blinding patients in a pragmatic trial is unrealistic, and does not adhere to the real world nature of this type of evaluative research. An unsuccessful attempt to blind the research assistant to a patient's allocation in this study was made. Whilst it is conceivable that this may have the potential, albeit remote, to bias the results, it is worth considering. In mitigation, the research assistant did not have any formal 'stake' in the study, and there were no funding implications for the success, or otherwise, of the study intervention.

The selection of outcome assessment tools used in the trial was influenced by current practice in stroke rehabilitation research. Homogeneity of both intervention and outcome assessment tool is essential for the combination of data across studies during systematic review. It is also desirable to achieve some degree of breadth, using appropriate theoretical frameworks, in relation to the types and level of outcome domains that can be assessed. In addition to the content of outcome assessment tools, the quality of a clinical trial will largely be governed by the quality of performance of the assessment tools it uses.

Whilst indicators of the validity and reliability of the assessment tools used in this study were available in the literature, their responsiveness had received little attention. This issue is particularly relevant for this study, where the anticipated effects of the intervention were essentially psychosocial in nature, and unlikely to be large. The literature would suggest that responsiveness refers to the ability of a assessment tool to identify changes in health that are clinically important (Guyatt, Deyo, Charlson *et al*, 1989). Increasingly however it is recognised that, whilst difficult to determine, responsiveness should include the ability to detect change which has importance to patients (Fitzpatrick, Davey, Buxton *et al*, 1998). The important consequence of focusing on relatively small psycho-social aspects of recovery is the demand it places on considerably larger trials across stroke populations.

It is easier to determine the effectiveness of health care interventions that have dramatic effect on physical outcomes such as mortality than interventions where the effects may be diffuse and subtle (Pocock, 1983). The stated aims of this trial intervention related mainly to adaptation and coping, rather than recovery in the traditional sense. Rehabilitation research has yet to demonstrate a strong, tested theory that links, for example, motivation, physical ability, social resources and quality of life (Clarke, Black, Badley *et al*, 1999; Wyller and Kirkevold, 1999). It is only possible therefore to postulate on the mechanisms that link the trial intervention to changes in the outcomes assessed. In some respects the encouraging findings of the associated study of intervention acceptability highlights some possible explanations and suggestions. Here, the fact that the stroke nurse appeared to be able to resolve problems may have improved aspects of emotional health. Whether these improvements in emotional health were a

precursor for experimentation and other work towards recovery is unclear. It is unlikely however that the trial intervention has a direct impact on physical function, if it has an impact at all. In terms of physical ability however, it is possible that the trial intervention assisted in the development of new ways of performing activities, albeit masking a reduction in physical function. Attempting to capture these patient-focused aspects of recovery from stroke is notoriously difficult. This discussion highlights the need for considerable work to be continued in this area.

Statistical issues

The most frequent descriptors of central tendency used in the trial were the median and interquartile range. Alternative approaches to explaining variation within either the control or experimental group were also used, including cross-tabulation or a mean and 95% confidence interval. This approach to the description of stroke outcome data has, for example, been used successfully elsewhere (Ebrahim, Barer and Nouri, 1986).

For some outcome assessment tools used in stroke rehabilitation research, the range of possible scores is relatively small, for example, the Barthel Index or the Caregiver Strain Index. In addition, when used in this clinical population there is the potential for prevalent physical symptoms to precipitate common score profiles, there is a significant potential for non-normal distribution of outcome scores. There is however little consistency in reporting the normality of patient data, and consequently presenting a justification for the selection of statistical tests.

The original power calculation indicated a target for recruitment which was not achieved. Whilst the actual sample size compares favourably with stroke rehabilitation research, and nursing research in particular, it does mean that detectable effect sizes had to be considerable. It is unlikely that this trial had much power to detect subtle changes in patient outcome. The targets set for statistical power and the actual sample size obtained indicate that this trial had the capacity to detect the moderate standardised difference in the outcomes assessed of 0.35 (Altman, 1982). This reinforces the need for larger trials of interventions in stroke rehabilitation research, particularly when they relate to psychosocial domains of recovery. An essential prerequisite for larger trials in this area is however an increased recognition of the relative importance of psychosocial interventions, and agreement on methods for their evaluation in clinical practice. This recognition and agreement must be placed within the context of multi-professional practice.

Patient management

The exceedingly low proportion of patients withholding consent may attest to any or all of the following themes identified in the associated study of intervention acceptability

- Acceptability of the intervention
- Positive relationships with the staff delivering the study intervention

In addition the consent procedures will have altered to some patients the potential to receive more services. Whilst it is not possible to establish the reasons why each patient decided to opt for inclusion in the trial, and to be randomised, it is likely that all three scenarios are important.

The flowchart depicting the management of patients in the trial demonstrates clearly that violations of the study protocol were dealt with according to the established principles of the pragmatic clinical trial. Forster and Young (1996) maintained that an intention-to-treat analysis was adopted in their evaluation of specialist nursing, where all available data was used. Their study did not however attempt to explore the impact of missing data, the proportion of which rose to nearly 50% at twelve months for the primary outcome. This is 11% higher than the proportion of missing data for the primary outcome in this trial. The study reported by Folden (1993) was manifestly not managed in a pragmatic manner as patients were excluded if they failed to complete the study intervention.

The demands placed on the consistency of findings when the impact of missing data is explored are considerable. Perhaps this may point in some way to the paucity of reporting for this feature of data analysis in stroke rehabilitation research. There is however a recognition that the standard techniques for considering missing data, including those used in this study, are immature in terms of their theoretical and practice development (Shih, 2002). Their execution in this study should therefore be seen as an indication of caution about validity rather than a more formal attempt at confirmation, or otherwise.

Perceptions of general health

The effects of the study intervention on perceptions of general health were generally consistent across the three and twelve month assessment point, with significant reductions in perceived social isolation and emotional distress. The key window of recovery that appeared to be affected by the study intervention was

after the three month assessment point, where changes in perceived general health were more marked. A Barthel Index score at randomisation of more than fourteen was however identified as a key factor in determining perceived general health up to the three month assessment point.

There are two potential explanations for this pattern of outcome: either that the provision of the study intervention prevented short-term improvement in outcome, or that the study intervention facilitated the development of medium to long-term recovery. There were however no significant differences between the two groups at the three month assessment point. This would suggest that the benefits of the study intervention may be delayed. One half of all activity undertaken by the stroke nurse in the trial was categorised as therapeutic using the definitions developed in this thesis. As established, the anticipated outcomes of therapeutic nursing care are essentially medium to long-term, focusing primarily on coping and adjustment to the consequences of stroke.

Whether supportive interventions can be detrimental to patient recovery is an issue that has previously been highlighted in the stroke rehabilitation literature (Dennis, O'Rourke, Slattery *et al*, 1997). In a pragmatic trial of a family support worker intervention, although the intervention won qualitative support from patients and carers, its effectiveness was disappointing. In respect of helplessness, social adjustment and depression the intervention appeared to have a deleterious effect. The study concludes that, given the usual threats to internal validity, the intervention may have precipitated a degree of passivity on the part of patients. Despite the social work background of the individual delivering the study intervention, little examination of how this might have affected intervention

delivery is not given. From a practical perspective, the information on the work of the family support worker that is provided relates to fulfilling unmet need through the use of available resources.

This trial intervention was however administered by a stroke nurse who had considerable experience of working with people affected by stroke. The interviews with the stroke nurse conducted as part of the study of the practice context of the intervention demonstrate an awareness of partnership and empowerment in working with stroke patients, supporting the established definition of therapeutic nursing in stroke rehabilitation. It may be that the partnership that developed between the stroke nurse and experimental group patients focused on rehabilitation, with an emphasis on patient activation, and working for recovery. This is an aspect of rehabilitative practice that is extremely difficult to explore, although the analysis of goals for rehabilitation has been used before (Lawler, Dowswell, Hearn *et al*, 1999). Unfortunately there is little theoretical work to link a strategy for goal setting in rehabilitation to patient activation (Bryan and Locke, 1967). For example, if a goal is achievable then does it necessarily motivate a patient to achieve it? If a goal is 'hard' to achieve does this have more of an activating effect? More research is required in this area that explores the relative effectiveness of alternative strategies for goal setting.

Forster and Young's (1996) study failed to demonstrate any statistically significant benefit of their study intervention in terms of Nottingham Health Profile scores. As the closest study to this trial identified in the systematic review, there are a number of possible reasons why different results have been found, including

- Differences in study validity leading to an increase in Type 1 error in this study
- Key differences in the study interventions

Whilst this is a pragmatic trial, attempting to reflect the realities of clinical practice, the profile of results appeared broadly consistent across time frames, and after completion of a sensitivity analysis for missing data. This would suggest that the study intervention does have some real advantages over the intervention tested by Forster and Young. In practical terms the most obvious difference between the two interventions is the provision of an overarching perspective from acute inpatient care to the community. In this way, experimental group patients were given the opportunity to maintain a therapeutic relationship with the stroke nurse, who in turn was able to understand individual cases to a greater and deeper degree. Whilst this was a key theme to emerge from the associated study of the practice context of the intervention, patients and carers did not directly refer to this in the associated study of intervention acceptability. Here a key theme was the development of realistic expectations in patients and carers, which may have produced some benefits in terms of an improved understanding and therefore perception of health.

The key subsections of the Nottingham Health Profile that were affected by the study intervention were emotional reaction and social isolation, both of which demonstrated benefit. At the three month assessment point pain appeared to be reduced in the experimental group, although this only approached statistical significance. The analysis of types of interactions between the stroke nurse and experimental group patients demonstrated that a significant proportion of care giving activity related to medication. It is not unreasonable therefore to suggest

that the study intervention may have short-term benefit in this aspect of clinical practice, and warrants further attention.

Physical dependence

The study intervention was not designed to enhance physical dependence, although the data did demonstrate that experimental group patients appeared to receive some benefit, again after the three month assessment point. The differences between the two groups were however relatively small, with only 13% of the control group and 6% of the experimental group recording a change in Barthel Index score of over two units in either direction from three to twelve months. This would suggest that any benefit the study intervention may provide is essentially protective, preventing decline in physical dependence after three months. The difference between the change in the Barthel Index scores is surprising as this was not reflected in the physical mobility subsection of the Nottingham Health Profile. Here the median change in both groups from the three to twelve month assessment point was zero (interquartile range of 22.88 in the control group and 12.61 in the experimental group). This perhaps may be partly explained by differences in the object of assessment. The Barthel Index assesses actual levels of dependence, whereas the Nottingham Health Profile assesses patients' perceptions of physical mobility. The overwhelming catastrophe of stroke evidenced in much of the qualitative research referred to in Chapter Two would suggest that this may precipitate discrepancy between actual and perceived performance. As such these are potentially different domains of outcome, and the inclusion of both in a stroke rehabilitation trial should be considered. Whilst physical dependence was not assessed in the Folden (1993) trial, the Forster and

Young (1996) study did not demonstrate any significant impact of their intervention. This would suggest that, given that the theoretical link between the study intervention and physical dependence is weak, that this protective effect identified in the Barthel Index scores may be a statistical artefact, and should therefore be treated with caution.

Social activities

Whilst the Frenchay Activity Index failed to demonstrate any significant benefit of the trial intervention, the Nottingham Health Profile sub-section demonstrated statistically significant reductions in social isolation. Inspection of the medians demonstrates that the differences between the two groups of patients were approximately 10% at three months and 25% at twelve months, representing a clinically important difference. The items relating to social isolation in the Nottingham Health Profile relate principally to perceptions, rather than the actual performance of activities in the Frenchay Activity Index. This would suggest that whilst the trial intervention may not have significantly improved performance, it may have improved patients ability to manage psychologically with restrictions in activities of living.

One key theme that emerged in the associated study of intervention acceptability was supporting the development of a realistic expectation for recovery on the part of patients and carers. As such it may be that by bringing expectations and 'felt' recovery closer together, the stroke nurse was able to facilitate more acceptance on the part of patients and carers.

The associated study of intervention intensity demonstrated some activity on the part of the stroke nurse in helping patients to cope with physical limitations and challenges. If this was to have any significant effect on patient outcome, it would seem reasonable that this would most likely to be demonstrated by the Frenchay Activity Index. Whilst this study did not detect any effect in terms of Frenchay Activity Index score change, the study reported by Forster and Young (1996) did demonstrate the potential of their intervention for those people with mildly physical disabled patients and randomisation. This would suggest that this type of supportive intervention may have some potential to improve recovery by helping people to adapt to the physical consequences of stroke, however this issue needs to be studied further.

The relationship between physical and social recovery after stroke remains poorly understood. It would appear that physical function may only explain to some degree the ability of patients post-stroke to perform activities of living, such as those assessed by the Frenchay Activity Index. There would appear to be a clear distinction between ability and social role, which may partly explain the discrepancy between the social isolation sub-section of the Nottingham Health Profile and the Frenchay Activity Index. Certainly, the theoretical work underpinning this study intervention would suggest that its principal focus lay in the psychological aspects of recovery. The need to develop a comprehensive theory linking the different components of recovery is pressing.

Depression

Knowledge of post-stroke depression is limited to incidence and prevalence, with little understanding of antecedent factors. The presence of depression may indicate the overwhelming catastrophe of the disease in individual terms, physical damage to brain tissue, or a combination of both.

In trials identified in the systematic review, depression was ignored in the Folden (1993) study, and only referred to indirectly in the Forster and Young (1996) study. Here a score of 30 or more on the Nottingham Health Profile was taken to infer depressed mood. This cut-off point has been demonstrated to have high sensitivity and specificity with the General Health Questionnaire (Ebrahim, Barer and Nouri, 1986). On this basis it would appear that the prevalence of depression at 12 months in the two trials was similar: 32% in the Forster and Young trial, and 20% in this trial.

Whilst this study failed to demonstrate any statistically significant effect of the experimental intervention on depression as assessed by the Beck Depression Inventory, the study does reinforce the importance of depression as a consequence of stroke. The Nottingham Health Profile sub-section, emotional health, was however consistently scored lower by experimental group patients. This discrepancy may be due to a number of factors, including:

- the two tools are assessing different attributes
- they have different abilities to detect clinically important change, or
- the discrepancy is a product of random error.

Given the consistency of differences in the emotional reaction subsection of the Nottingham Health Profile, it is unlikely that random error has a significant part to play in the explanation of group differences. Whether the two tools are assessing different attributes may be explored by examining the correlation between scores. The Spearman correlation coefficient was 0.68 at the three month assessment and 0.63 at the twelve month assessment, both coefficients being significant at the 0.01 level. This would suggest that the Beck Depression Inventory and the emotional reaction subsection of the Nottingham Health profile are assessing different but related aspects of mental health (Streiner and Norman, 1995).

Inspection of the items included in the Beck Depression Inventory and emotional reaction subsection of the Nottingham Health Profile demonstrates that the tools contain items relating to similar issues. There are substantial differences in the structures of the tool with what would appear to be a greater degree of responsiveness in the Beck Depression Inventory, where each item can score from zero to three. The items relating to emotional reaction in the Nottingham Health Profile are interspersed with items relating to other domains of health, and the binary structure of responses makes it an easier tool to complete. The relative complexity of the Beck Depression Inventory and the repetitive nature of its structure may however limit its responsiveness. At a practical level this issue is recognised in the instructions for use, where it is recommended that a consistent profile of responses should be challenged in interview (Beck, Steer and Brown, 1996).

A final explanation may be that whilst the study intervention may have positive effects on patient mental health, the trial did not have sufficient power to detect

changes in Beck Depression Inventory scores. Indeed there are a substantial proportion of missing data for this tool: 9% at the three month assessment point, and 34% at the twelve month assessment. In addition, only 65% of patients have changes in scores from three to twelve months available for analysis. Certainly, a key aspect of the work of the stroke nurse in delivering the trial intervention was depression, including liaison with general practitioners and hospital staff regarding anti-depressant therapy which lends weight to the benefits seen in the Nottingham Health Profile data.

In any case, the trial would suggest that the formal assessment of depression using the Beck Depression Inventory in an investigation of a similar intervention is warranted, and should be sufficiently powered to detect clinically important changes in depression.

Carer strain

The study intervention augmented existing clinical practice, providing enhanced support to patients and carers in the immediate period after hospital discharge. It is unsurprising therefore that carers of patients in the experimental group reported less strain at the three month assessment period. The data demonstrates however that this effectiveness may be short-term, and therefore dependent on continued receipt of the study intervention. The associated study of intervention acceptability did not generate any data that can illuminate this pattern. It did however highlight the fact that the stroke nurse worked with both patients and carers, providing a resource for both.

The Forster and Young (1996) trial also examined the effect of their study intervention using a cut-off of five points on the General Health Questionnaire. Whilst no statistically significant differences between carers of experimental and control group patients was demonstrated, they identified a general trend in the data where carers levels of stress improved over time.

The effectiveness of interventions specifically designed to help carers adjust to the consequences of stroke within a family is generally disappointing (Dennis, O'Rourke, Slattery *et al*, 1997). The study of social problem-solving partnerships with family caregivers reported by Grant (1999) does however appear promising. Whilst only a small, quasi-randomised study, the potential benefit of training carers in problem-solving was highlighted. Training was provided to carers by qualified nurses, and was designed to improve the care-giving experience. The data demonstrated that training was effective in promoting a sense of preparedness.

The issues faced by carers of people affected by stroke have tended to be approached from the implicit maintenance of a status quo, by focusing on carer health, stress and strain (Brereton and Nolan, 2000). This stresses the importance of ensuring carers are 'fit for purpose' rather than empowering them to develop and maintain new caring roles as needs, priorities and resources change over time. Grant's (1999) paper suggests an approach which may be useful in empowering carers, although this requires development and testing in the UK.

Relationship to the evidence-base

The evidence-base for the repertoire of therapeutic nursing interventions is essentially weak and diffuse. This may partly be a product of a lack of understanding of what the nursing contribution to stroke rehabilitation is or could be, and the paucity of rigorous clinical nursing research in general.

A systematic review of the literature yielded few studies that explored the effectiveness of therapeutic nursing interventions in stroke rehabilitation. One study examined the effectiveness of specialist nursing in providing information and advice to stroke patients in the community (Forster and Young, 1996). The results of this study were generally disappointing, although the intervention won qualitative support from those affected by stroke. The study lacked a strong theoretical framework, and as consequence it is difficult to establish whether nurses in this study did in practice use a therapeutic approach. One study was however identified that included the testing of a clearly established therapeutic nursing intervention in acute stroke care (Folden, 1993). What was particularly disappointing about both of these studies was the narrow focus that both took in considering the complete picture of stroke as a disease process. This is surprising given the well documented challenges that those affected by stroke face as they cross from hospital to community services. This is the only study that has been identified that specifically addresses an enhanced service to patients during this critical time in their recovery. This study therefore represents a new addition to the evidence-base for stroke rehabilitation practice, testing an over-arching perspective spanning hospital and community through the provision of a therapeutic nursing intervention.

Implications for clinical practice

This study would suggest that the provision of an overarching perspective in the organisation of stroke services, through a therapeutic nursing intervention that focuses on adaptation to psycho-social consequences, is effective in improving patients' perceptions of their health. Specifically feelings of social isolation and negative emotional reaction are reduced. In addition, providing this type of intervention may, in the short term, have

- a protective function in terms of physical independence,
- an ability to reduce perceived pain, and
- an ability to reduce carer strain in the short term.

The data demonstrates some disparity between actual and perceived levels of ability, particularly in terms of social activation. It would seem that a key feature of the intervention's effectiveness is the promotion of acceptance of, and coping with the consequences of stroke. This is an important aspect of psycho-social recovery, and can be alluded to in terms of the perceived acceptability and utility of stroke services. The relationship between these aspects of recovery is topical given the renewed interest in the perspectives of service users in health care policy, and therefore warrants further attention.

Increasing recognition of the potential overwhelming catastrophe of stroke in all aspects of a patient's world has highlighted the importance of the psycho-social dimension of recovery. Services or intervention designed to improve this aspect have consistently been shown to be lacking in patient focused research. The importance of expanding the research-base for this aspect of rehabilitation

practice has been recognised for a considerable amount of time (University of Leeds, 1992).

It has been suggested that whilst short-term interventions may be successful in facilitative recovery, particularly in relation to health education and promotion, the benefits may in turn be of short duration. Whether this is due to receptivity in the early stages of recovery, or that supportive interventions are rarely more than three months in duration is unclear (Redfern, McKevitt, Dundas *et al*, 2000). The data in this study would suggest however that the potential of therapeutic nursing lies in the medium to long-term. The key improvements in patient outcome were most noticeable after three months, although few patients in the experimental group received the study intervention after this point.

The research relating to support for people affected by stroke relates in the main to information giving. This is the easiest aspect of support to identify, and consequently to study in evaluation research. Cohen and Wills (1985) maintain that information giving is only one aspect of providing support, which also includes emotional support to promote self-esteem, coaching for recovery and tangible support. This last aspect suggests an acceptance of a status quo in terms of recovery, and relates to the care giving function of the nursing role identified by Burton (2000c). The purpose of this care is only indirectly linked, if at all, to recovery. Coaching, with the provision of information and emotional support, is strongly suggestive of recovery, incorporating the appraisal of performance with reinforcement.

If nurses are to capitalise on their ability to provide a therapeutic contribution to the stroke multidisciplinary enterprise, then formal strategies for the provision of therapeutic care need to be established, and their relative merits tested. To do this however requires a considerable amount of observational research to be undertaken to develop the framework of therapeutic nursing in stroke rehabilitation. This study has the potential to provide some impetus to this activity.

The predominant purpose of rehabilitation services is to enhance independence by facilitating improvement in the performance of activities of daily living by patients. Whilst this is a laudable aim, it does little to reinforce the importance of psycho-social recovery in stroke rehabilitation. In addition, there is a pressing need to explore how those with residual deficits in function, ability and handicap can best be served by healthcare. Much of the research into long-term rehabilitation focuses on the 'more of the same', usually therapy, approach, rather than adaptation to the physical, emotional and social consequences of disease. There is an implicit danger that health care services can be seen to neglect those in whom no further physical function can be developed.

This study demonstrated that it is possible to successfully deliver a complex intervention in flexible manner, responding to patient needs and priorities for recovery. This would appear to challenge the predominant shift in service development towards the micro skills and competencies as a key driver for professional development. It is relatively easy to translate these aspects of professional practice into auditable models of clinical governance. This perhaps explains the temptation to address the governance of nursing care in this manner,

which has inevitably been overwhelming in many clinical areas, and in particular (Watson, 2002). The theory and performance of this trial intervention do not however sit comfortably with the inherent reductionism involved in developing and measuring competency in healthcare.

Implementing this type of intervention into clinical practice requires however the careful consideration of four issues

- vicarious liability
- education and training
- managerial support
- multiprofessional support

Vicarious liability for the development of new nursing interventions rests in their process of development and support in clinical practice. The development of this trial intervention required extensive collaboration between researchers and nursing management to ensure staff were adequately prepared for its delivery. In addition, the theoretical framework for therapeutic nursing in stroke rehabilitation provided a blueprint strategy in which practical implications could be explored, and flexible boundaries for practice established. The provision of ongoing professional support and supervision is required to support practitioners developing new roles where boundaries are flexible, and open to interpretation.

A bespoke development and training package was undertaken by the stroke nurse in the preparatory phase of the trial to support implementation of the trial intervention. The package included shadowing the clinical practice of specialist occupational therapists and physiotherapists, and the Community Psychiatric Liaison Nurse. It must be recognised that as a new intervention, problems may

arise in its interpretation by stakeholders including management and other disciplines which will have the capacity to hamper its effectiveness. Whilst it was hoped that the formation and maintenance of a steering group would reduce the potential for problems to arise, the associated study of professional context demonstrated that some problems still arose, but were resolved relatively easily. It is clear that although considerable energies may be spent in preparing to expand nursing practice in this way, the continuation of support and supervision after implementation are crucial.

Implications for health care policy

The National Service Framework for Older People (Department of Health, 2001a) has undoubtedly regenerated interest in stroke and rehabilitation. Policy relating to stroke services is however diffuse, and distributed amongst a number of governmental strategies. More specifically the National Clinical Guidelines for stroke provide a strategic focus for the development of services for this patient group.

The strength of evidence relating to the structure and organisation of stroke services provides a clear benchmark for the development of services generally. There are however a number of limitations in current stroke policy which require further attention. Firstly the National Service Framework does little to challenge the organisation of stroke services to better reflect the concerns and priorities of stroke patients and carers. In many respects the framework does little to challenge the traditional model of service organisation around a two-stage model of rehabilitation. The introduction of intermediate care presents an opportunity to

refocus the organisation and timing of traditional approaches to stroke rehabilitation. Together with the Single Assessment Process, these developments may present an opportunity to improve the co-ordination of follow-up services for stroke patients. Both of these changes to policy do little however to reflect the fact that the long-term needs of this patient group are complex and dynamic, and will therefore be sensitive to change over time.

One study of an essentially psycho-social intervention in stroke rehabilitation can hardly be expected to significantly challenge existing policy. The themes of this study intervention, flexibility, patient-sensitivity and long-term recovery do not sit comfortably with approaches to health care policy that are geared towards demonstrable, short-term achievable targets. The major health care policy implication from this study is that it is possible to develop interventions that transcend existing ways of working for the benefit of patients.

The research also stresses that the assessed and perceived reality of recovery from stroke can differ significantly in an individual patient. The utility of achieving actual or perceived gain may be diminished if both 'real' and felt recovery are not synonymous. As such approaches to the development and evaluation of stroke service in both policy and practice should include a focus on both elements of recovery.

Implications for research

From the point of method, this thesis has demonstrated that the pragmatic randomised controlled trial is a suitable and feasible design for the evaluation of

therapeutic nursing interventions. The use of the Medical Research Council (2000) framework for the development and evaluation of complex interventions presents a useful strategy to influence the design of such an evaluation. The framework does highlight the importance of theoretical work, or modelling, in the identification of active components of a complex intervention. Whilst this complex trial intervention has been strongly underpinned with current theory, further observational research is required to investigate those components of therapeutic nursing practice which are most effective. It is hoped that this study has the potential to provide some impetus to this activity.

Whilst the clinical effectiveness of this study intervention is promising, there is a need to establish its merits in larger stroke populations and in different locations. This study has established a benchmark for the design of further investigations of therapeutic nursing in stroke rehabilitation, providing, for example, information on the performance of outcome assessment tools. It is suggested that further research in this area should also focus on the components of therapeutic nursing, and include more detailed structured analysis of therapeutic content. The framework for therapeutic nursing, coupled with the qualitative information obtained in the associated studies could provide the basis for this work.

This study inevitably leaves many questions unanswered, particularly in the explanation of patterns of felt and 'actual' recovery from stroke, and the role of professional health care in addressing these aspects. There is a growing body of evidence about the effectiveness of stroke services, although the psycho-social research base is relatively immature. It is hoped that this study will contribute to

its development, and in particular the emergence over time of some theoretical consistency in explaining, and improving life with stroke.

Conclusions

A framework to describe the therapeutic function of nursing in stroke rehabilitation has been developed which focuses on

- the concerns and priorities of those affected by stroke rather than purely professional priorities for recovery,
- using the nurse-patient relationship as a medium for education and support
- adjustment to life with stroke through the development of effective coping mechanisms, and
- the development of meaningful social worlds for living with the consequences of stroke.

The framework has been used to underpin the development of a new nursing intervention that builds on existing clinical practice. Here the ability of a stroke nurse role to provide education and support for recovery across the existing boundaries of service provision was extended to more closely mirror recovery from the perspectives of stroke patients. This development has been demonstrated to be feasible in clinical practice, although it requires considerable multidisciplinary and managerial support for successful implementation.

A pragmatic randomised controlled trial has demonstrated that implementing the nursing intervention has the potential to improve patient perceptions of general health, and in particular to reduce negative emotional reaction and perceived social isolation. This effectiveness appears to be delayed, and was detected at least

three months after stroke. In addition there may also be a delayed effect in protecting physical independence, again at least three months after stroke. The intervention may have immediate benefits in improving the management of pain and in reducing carer strain. The focus of assessment tools that demonstrated the effectiveness of the study intervention, coupled with the qualitative exploration of the intervention context and acceptability, would suggest that its benefits may principally be in helping people to adjust to, and cope with the consequences of stroke.

Recommendations

A number of recommendations can be made on the basis of this research.

- That the therapeutic function of stroke rehabilitation nursing be strengthened through consideration in clinical practice of the framework developed in this thesis.
- That stroke service management gives serious consideration to the provision of a therapeutic nursing role, delivered in an overarching perspective spanning the traditional boundaries of service organisation.
- That where therapeutic nursing interventions are implemented, then this is undertaken in consultation with multi-disciplinary colleagues and management, and with ongoing professional supervision.

- That where implemented, therapeutic nursing interventions are subject to ongoing evaluation to establish the generalisability of these study findings, and to explore the relative effectiveness of their therapeutic content.

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Appendix 1
Ethical Approval Confirmation

WEST LANCASHIRE LOCAL RESEARCH ETHICS COMMITTEE

Chairman: Mrs D Howel
Administrator: Mr E H Albery
Telephone: 01695 583080
Fax: 01695 583028

West Lancashire Local Research Ethics Committee
c/o Trust Headquarters
Ormskirk and District General Hospital
Wigan Road
ORMSKIRK
L39 2JW

Our Ref: EHA/HCF/C8(B)

21 October 1999


Mr C Burton
Senior Lecturer
Department of Primary & Community Nursing
University of Central Lancashire
PRESTON
PR1 2HE

Dear Chris

STROKE OUTCOMES TRIPARTITE RESEARCH PROGRAMME

Following verbal approval, I am writing to confirm that the above Study has been approved by this Committee. As you are aware, North Sefton Local Research Ethics Committee has details of your Study for consideration. I will speak to my counterpart at Southport next week and advise you accordingly.

Yours sincerely



E H ALBERY
ADMINISTRATOR – West Lancashire Local Research Ethics Committee

**Pharmacy Office
Southport & Formby District General Hospital
Town Lane, Southport, Merseyside PR8 6PN
Tel: 01704 864165
Fax: 01704 502008**

Response Form for LREC-approved study

19 November 1999

Mr C R Burton
Department of Primary & Community Nursing
University of Central Lancashire
PRESTON
PR1 2HE

Dear Mr Burton

**RESEARCH PROTOCOL (303) EVALUATION OF ADVANCED NURSING PRACTICE IN
STROKE REHABILITATION
WEST LANCASHIRE LREC Ref.No. EHA/HCF/C8(B)**

Following ethical review by West Lancashire LREC, a sub-committee of NSLREC has considered the suitability of your study in respect of local factors. The sub-committee is particularly interested in the following:-

1. **The suitability of the local researcher:** Self-explanatory.
2. **The suitability of the local site:** Local clinical environment and facilities.
3. **The suitability of the subjects:** To prevent over-research of local population or patient groups. There may be other reasons why the proposed local subjects are not suitable.
4. **The patient information sheet and consent form:** Local information (such as contact numbers and addresses) should be included. The forms should be appropriately headed and written in a language appropriate for the local subject.

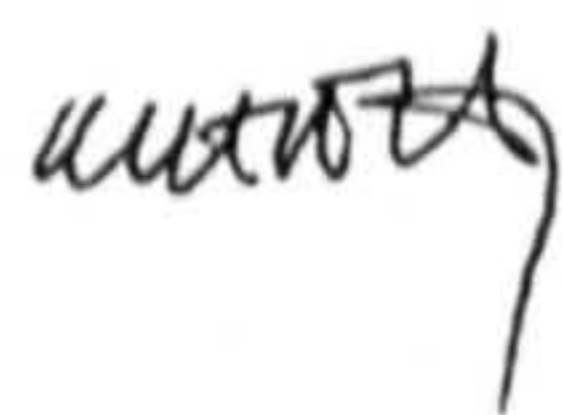
The sub-committee met and considered the protocol. Their comments were as follows:-

- **No local objections to the study. Permission to proceed granted. Conditions of approval are as indicated in the correspondence from the authorising LREC.**
- **The submission was rather turgid and jargon-led.**
- **Your study was first submitted to West Lancs LREC in April 1999. Since then there has been national agreement on what constitutes an acceptable consent form and information sheet (enclosed). Under the circumstances, as we do not wish to modify your protocol which has already been approved, we do not feel we need to insist on your using the new forms in Southport. If at any time you were contemplating an amendment to this study, we would insist upon an improvement to the consent form and information sheet.**

19 November 1999

Mr C R Burton

Yours sincerely



M ABBOTT
Chairman
North Sefton Local Research Ethics Committee

Copy to: Mrs D Howel
Chairman
West Lancashire LREC
Ormskirk DGH

Mrs G Dolan
Group General Manager
Medical Management & Performance Group
Southport & Ormskirk Hospital NHS Trust

Appendix 2

Study Information Sheet

REHABILITATION SPECIALIST NURSE STUDY

PATIENT INFORMATION SHEET

- 1.0** The study that you have agreed to help us with refers to an investigation of aspects of the rehabilitation nurse specialist role.
- 2.0** You will receive all the usual care and support provided to patients following discharge from hospital. You may, however, receive additional visits at home from the rehabilitation nurse specialist. All of the professionals (nurses, doctors, physiotherapists etc.) who would usually be involved in your care will continue to be involved. Your GP and community care professionals will continue to be informed of the services provided for you.
- 3.0** At 3 and 12 months after you go home from hospital, you will be contacted by telephone to arrange an appointment with a member of the research team. This person will, depending on which you prefer, visit you at home or see you in the hospital, to ask you some questions about your health and check on your progress. You will be informed of the name of the person who will talk to you, and they will carry an identity card with them. We would encourage you to have a member of your family, or a family friend with you at this time.
- 4.0** All details collected as part of the study will be kept confidential to the research team. The data we collect will be used to highlight the results of the project. All results, however, will be reported anonymously. No-one will be able to identify you.
- 5.0** You can withdraw from the project at any time by contacting:

(Name), Rehabilitation Nurse Specialist

Telephone: (Telephone number).

If you decide to withdraw your care will not be affected in any way.
- 6.0** Please remember to inform (Name) if you move house, or your contact details change in anyway.

Many thanks for taking the trouble to help us.

Appendix 3

Consent Form

UNIVERSITY OF CENTRAL LANCASHIRE LOGO

Name:
Hospital Number:

Address:

Dear

Re: Investigation of rehabilitation nursing practice

The rehabilitation units at (Hospitals) are undertaking a research project with the University of Central Lancashire. The project examines the type of support you receive from the rehabilitation specialist nurses when you go home. We would welcome your help in this study.

If you agree to participate, the normal care and support that all people receive will not be altered in any way. You may, however, receive additional follow-up visits from a specific nurse from the rehabilitation unit at the hospital. In addition a researcher will make two appointments with you to talk to you about your health either in your home or at hospital.

You will be free to withdraw from this study at any time by telephoning the Rehabilitation Nurse Specialist (Name) on (Telephone number). If you do this, your care will not be affected in any way.

Yours sincerely

Christopher R Burton
Department of Primary and Community Nursing

Name: Hospital Number

Name:(if next of kin)

I agree to participate in the above research study. I have received an explanation of the study which I understand, and have read the research information sheet. I realise I will be able to withdraw from the study at any time without prejudicing my care.

Signed:

Date:

Witness:

Trial Registration Form

STROKE OUTCOMES TRIPARTITE RESEARCH PROGRAMME

TRIAL ADMISSION SHEET

HOSPITAL:

Patient details

Name:

Address:

Sex:

DOB:

Telephone number

Next of kin:

Contact details

Relationship:

General Practitioner:

Name:

Practice address:

Exclusion criteria:

Previous clinical depression:

YES / NO

Multi-infarct dementia

YES / NO

Concurrent medical condition

YES / NO

Chemical dependency

YES / NO

Diagnosis:

First or subsequent stroke?

Date of admission:

Date of discharge:

Discharge destination:

Activity	Ability	TICK	Score
Bowels	Incontinent (or needs enema)		0
	Accident up to once a week		1
	Continent		2
Bladder	Incontinent or catheter		0
	Accident up to once a day		1
	Continent		2
Grooming	Needs help with personal care		0
	Independent (may be given items)		1
Toilet	Dependent		0
	Needs some help		1
	Independent		2
Feeding	Unable to feed self		0
	Needs some help, like cutting food		1
	Independent		2
Transfer	Unable, has no sitting balance		0
	Needs major help (physical)		1
	Limited help (verbal)		2
	Independent		3
Mobility	Immobile		0
	Wheelchair independent		1
	Walks with one person		2
	Independent		3
Dressing	Dependent		0
	Can do about half unaided		1
	Independent		2
Stairs	Unable		0
	Needs help		1
	Independent		2
Bathing	Dependent		0
	Independent		1
	TOTAL		

Stratification factors:

Factor	Level	Result
Hospital	A / B	
Stroke	First / Subsequent	
Discharge	Home / Continuing care	
Function	14 or less / 15 or more	

Date form completed:

Date York notified:

Randomisation result:

Stroke Specialist Nurse notified:

Appendix 5
Trial intervention and associated training needs

Trial intervention and associated training needs

Aspect of Intervention	Development need	Resources available
Review of physical function	Ability to screen for problems with swallow	Clinical practice with a specialist Speech and Language Therapist
	Knowledge of patient positioning	Regional Bobath trainer
	Knowledge of continence management	Regional network or continence nurse specialists
Patient and carer knowledge		
Ability to cope emotionally	Ability to identify risk of depression	Clinical practice with Community Psychiatric Liaison Nurse
Home environment	Knowledge of frameworks to assess home environment	Clinical practice with Occupational Therapist
Medication review	Knowledge of pharmacological issues relating to anti-coagulants, lipid-lowering drugs and ant-hypertensives	Pharmacy services and specialist physician
Transfer of care		
Health promotion	Knowledge of community based statutory and voluntary sector services	Carer's Association Stroke Association Primary Care Groups

Appendix 6

Patient Assessment Book



STROKE OUTCOMES TRIPARTITE RESEARCH PROGRAMME

PATIENT ASSESSMENT SCHEDULE

CONFIDENTIAL

PATIENT CODE:

MEASUREMENT DATE:

FIRST / SECOND MEASURE:

LOCATION OF INTERVIEW:

(If not at place of residence)

Consent

I agree to be interviewed, and understand that the content of the interview will be kept confidential to the research team. In the unlikely event that any serious problems to my health are identified referrals to health agencies will only be made with my consent.

Signed :

Witness:

ETHICAL ISSUES

The Beck Depression Inventory

All patients who are consented and randomised in to the study are assessed at 3 months and 12 months post discharge. Assessment of patients will include administration of the Beck Depression Inventory (BDI), usually in the patient's home. Assessments are undertaken by a research assistant employed by the University of Central Lancashire.

Item 9 of the BDI refers to the absence or presence of suicidal thoughts or wishes.

In view of the potential ethical issues in assessing this item, and others, identifying a serious threat to the patient's health, and withholding this information from health care professionals, the following protocol will be used:

1. All patients will be advised from the outset that the assessment of health outcomes is confidential. An exception may be made in the unlikely event that a serious threat to the patient's health is identified. **In this case the issue may be discussed with the patient.**
2. Where a serious threat to the patient's health is identified, a referral to the most appropriate health care professional may be made after discussion with the patient. **Written consent for any referral should be obtained from the patient.**
3. For patients discharged from Hospital B that score either 2 or 3 on item 9 of the BDI a same-day referral to (Psychiatric Liaison Nurse), will be made.
4. For patients discharged from Hospital A that score either 2 or 3 on item 9 of the BDI, a same-day referral to the patients General Practitioner will be made.
5. A record of any referrals will be made in the patient assessment book.
6. The data collector should use the research team for professional supervision if any concerns are unresolved after discussion with the patient.

1.0 INTRODUCTION

- 1.1** This schedule is structured as a self-contained manual to guide and record the assessment of patients and carers enrolled in the trial of advanced nursing practice in stroke rehabilitation.

2.0 Schedule structure

- 2.1** The schedule is administered within an interview framework. The interview is composed of 8 sections:

- Negotiating entry
- Confirmation of demographic data
- Assessment - Bartel index
- Assessment - Nottingham Health Profile
- Assessment - Frenchay Activities Index
- Assessment - Beck Depression Inventory
- Interview Closure

3.0 Administration

- 3.1** The administration of the assessment schedule is designed in such a way to maximise the rigor of the investigation. It is important therefore

- To keep to the 'script' as much as possible
- To refrain from wider discussion with the patient and carer about recovery from stroke

This must however be balanced with the importance of providing a positive and reassuring environment in which patients and carers can disclose sensitive information.

- 3.2** Prior to administration, the patient and / or carer will have been contacted to arrange a suitable appointment for assessment. They will have been told the name of the interviewer, and that the interviewer will be carrying a University Identification Card.

- 3.3** Administration will normally be undertaken in the patients' home. Where this is not the case, this should be recorded on the cover of the assessment schedule.

4.0 Patients unable to comply with assessment

- 4.1** Ideally all sections other than the Caregiver Strain Index should be completed by the patient.

- 4.2** Where the patient is unable to contribute to assessment then help from carers can be provided as indicated.

- Questions from the Barthel Index and Frenchay Activities Index section can be completed entirely by the carer

- Confirmation of the patient's response to any question from the Beck Depression Inventory or Nottingham Health Profile sections can be provided by the carer
 - Where the patient cannot contribute in any meaningful way to the completion of the Nottingham Health Profile, Beck Depression Inventory sections then these should not be scored
- 4.3** If the patient's carer is present, and the patient is able to answer assessment questions, then the Caregiver Strain Index can be given to the carer to complete away from the patient. Whilst the carer is doing this, the Bartel Index, Nottingham Health Profile, Frenchay Activities Index and Beck Depression Inventory can be completed with the patient.
- 4.4** Please note the circumstances of administration, including who completed which assessment
- 5.0 Script**
- 5.1** The sections in italics constitute the 'script' of the interview.
- 5.2** Boxed terms in small font indicate the content associated with each response. They may be used to prompt the patient or carer if necessary
-

NEGOTIATING ENTRY

Many thanks for continuing to agree to help us with the stroke study, and for agreeing to speak to me today. Most of my questions will focus on how you are coping, and how you are feeling.

Before we start I would just like to remind you that all information you give us is held strictly confidential and will only be used by the research team to help us in our work. Your answers will not be discussed with anyone involved in any care or health services you are receiving.

The only exception to this is in the unlikely event that a serious health problem is identified, when we will contact the relevant health care professional.

CONFIRMATION OF DEMOGRAPHIC DATA

First of all, I'd like to check some basic details.

*1. Have you changed your GP since <you were discharged from hospital> ?
<we last spoke>*

If YES, please record new GP details

General Practitioner:
Practice Address:

*2. Have you either been re-admitted to hospital or have you stayed in any health care institution since <you were discharged from hospital> ?
<we last spoke>*

(Available prompts are: *hospital, nursing home, respite care*)

If YES, please record the locations and purpose of each re-admission

3. Would you tell me what health services you are receiving at the moment?

(Available prompts are: *day-hospital, physiotherapy, district nurses, meals on wheels, home-care, home-help, occupational therapy*)

Please list with frequency

ASSESSMENT - BARTHEL INDEX

Many thanks for helping me with those questions. Next, I'm going ask some questions about key activities of daily living, such as how your mobility has been affected by your illness. For each activity I would like you to tell me if you are experiencing any problems at the moment.

NOTE: CAN BE COMPLETED BY CARER IF REQUIRED

Activity	Ability	TICK	(Score)
<i>Bowels</i>	<i>Incontinent (or needs enema)</i>		0
	<i>Accident up to once a week</i>		1
	<i>Continent</i>		2
<i>Bladder</i>	<i>Incontinent or catheter</i>		0
	<i>Accident up to once a day</i>		1
	<i>Continent</i>		2
<i>Grooming</i>	<i>Needs help with personal care</i>		0
	<i>Independent (may be given items)</i>		1
<i>Toilet</i>	<i>Dependent</i>		0
	<i>Needs some help</i>		1
	<i>Independent</i>		2
<i>Feeding</i>	<i>Unable to feed self</i>		0
	<i>Needs some help, like cutting food</i>		1
	<i>Independent</i>		2
<i>Transfer</i>	<i>Unable, has no sitting balance</i>		0
	<i>Needs major help (physical)</i>		1
	<i>Limited help (verbal)</i>		2
	<i>Independent</i>		3
<i>Mobility</i>	<i>Immobile</i>		0
	<i>Wheelchair independent</i>		1
	<i>Walks with one person</i>		2
	<i>Independent</i>		3
<i>Dressing</i>	<i>Dependent</i>		0
	<i>Can do about half unaided</i>		1
	<i>Independent</i>		2
<i>Stairs</i>	<i>Unable</i>		0
	<i>Needs help</i>		1
	<i>Independent</i>		2
<i>Bathing</i>	<i>Dependent</i>		0
	<i>Independent</i>		1

Please note that exemplars that set limits for each category level are available alongside this page

Exemplars for category levels for the Barthel Index

<i>Bowels</i>	Incontinent (or needs enema)	
	Accident up to once a week	
	Continent	
<i>Bladder</i>	Incontinent or catheter	A catheterised patient who can completely manage the catheter alone is CONTINENT
	Accident up to once a day	
	Continent	
<i>Grooming</i>	Needs help with personal care	doing teeth, fitting teeth, doing hair, shaving, washing face
	Independent (may be given items)	If implements need to be given but can manage the rest alone then INDEPENDENT
<i>Toilet</i>	Dependent	
	Needs some help	Can wipe self and do some of the below
	Independent	Should be able to reach toilet/commode, undress sufficiently, clean self, dress and leave
<i>Feeding</i>	Unable to feed self	
	Needs some help, like cutting food	
	Independent	Can eat any normal food. Food cooked and served by others.
<i>Transfer</i>	Unable, has no sitting balance	
	Needs major help (physical)	One strong/skilled person OR two 'normal' people
	Limited help (verbal)	One person helps easily or needs any supervision
	Independent	FROM BED TO CHAIR AND BACK
<i>Mobility</i>	Immobile	
	Wheelchair independent	Must be able to negotiate corners etc. independently
	Walks with one person	
	Independent	About domicile. May use aid.
<i>Dressing</i>	Dependent	
	Can do about half unaided	Includes help with zips, buttons etc. BUT can put on SOME items independently
	Independent	Should be able to select and put on all clothes (even if adapted)
<i>Stairs</i>	Unable	
	Needs help	
	Independent	MUST carry any walking aid up stairs to be independent
<i>Bathing</i>	Dependent	
	Independent	Must get in and out (of BATH OR SHOWER) and wash self unaided

ASSESSMENT - NOTTINGHAM HEALTH PROFILE

I am going to mention some things that some people say they have problems with in their everyday lives. For each thing I'd like you to tell me YES or NO as to whether you feel the same.

	please tick	YES	NO
<i>I'm tired all the time</i>			
<i>I have pain at night</i>			
<i>Things are getting me down</i>			
<i>I have unbearable pain</i>			
<i>I take tablets to help me sleep</i>			
<i>I've forgotten what it's like to enjoy myself</i>			
<i>I'm feeling on edge</i>			
<i>I find it painful to change position</i>			
<i>I feel lonely</i>			
<i>I do not get out much</i>			
<i>I find it hard to bend</i>			
<i>Everything is an effort</i>			
<i>I wake up in the early hours of the morning</i>			
<i>I'm unable to walk at all</i>			
<i>I'm finding it hard to make contact with people</i>			
<i>The day seems to drag</i>			
<i>I have trouble getting up and down the stairs</i>			
<i>I find it hard to reach for things</i>			
<i>I'm in pain when I walk</i>			
<i>I lose my temper easily these days</i>			
<i>I feel there is nobody I am close to</i>			
<i>I lie awake for most of the night</i>			
<i>I feel as if I'm losing control</i>			
<i>I'm in pain when I'm standing</i>			
<i>I find it hard to dress myself</i>			
<i>I soon run out of energy</i>			
<i>I find it hard to stand for long</i>			
<i>I'm in constant pain</i>			
<i>It takes me a long time to get to sleep</i>			
<i>I feel I am a burden to people</i>			
<i>Worry is keeping me awake at night</i>			
<i>I feel that life is not worth living</i>			
<i>I sleep badly at night</i>			
<i>I'm finding it hard to get on with people</i>			
<i>I need help to walk outside</i>			
<i>I'm in pain when going up or down the stairs</i>			
<i>I wake up feeling depressed</i>			
<i>I'm in pain when I'm sitting</i>			

I am now going to ask you some questions about some activities in your life that may be affected by your state of health. Please tell me again YES or NO if your present state of health is causing problems with the following:

	please tick	YES	NO
<i>Job of Work (paid employment)</i>			
<i>Looking after the home, such as cleaning cooking and odd jobs</i>			
<i>Social life like going out to the pub or seeing friends</i>			
<i>Relationships with other people in your home</i>			
<i>Sex life</i>			
<i>Interests and hobbies</i>			
<i>Holidays</i>			

ASSESSMENT - FRENCHAY ACTIVITIES INDEX

I'm now going to ask you some questions about how much or how often you are able to do certain things. For each question there are a few alternative responses. Please listen to each response and see which fits best to you.

NOTE: CAN BE COMPLETED BY CARER IF REQUIRED

<i>Preparing main meals in the last 3 months</i>	<i>Never</i>		0
	<i>Under once weekly</i>		1
	<i>1-2 times a week</i>		2
	<i>Most days</i>		3
<i>Washing up in the last 3 months</i>	<i>Never</i>		0
	<i>Under once weekly</i>		1
	<i>1-2 times a week</i>		2
	<i>Most days</i>		3
<i>Washing clothes in the last 3 months</i>	<i>Never</i>		0
	<i>1-2 times</i>		1
	<i>3-12 times</i>		2
	<i>At least weekly</i>		3
<i>Light housework in the last 3 months</i>	<i>Never</i>		0
	<i>1-2 times</i>		1
	<i>3-12 times</i>		2
	<i>At least weekly</i>		3
<i>Heavy housework in the last 3 months</i>	<i>Never</i>		0
	<i>1-2 times</i>		1
	<i>3-12 times</i>		2
	<i>At least weekly</i>		3
<i>Local shopping in the last 3 months</i>	<i>Never</i>		0
	<i>1-2 times</i>		1
	<i>3-12 times</i>		2
	<i>At least weekly</i>		3

<i>Social occasions in the last 3 months</i>	<i>Never</i>		0
	<i>1-2 times</i>		1
	<i>3-12 times</i>		2
	<i>At least weekly</i>		3
<i>Walking outside in the last 3 months</i>	<i>Never</i>		0
	<i>1-2 times</i>		1
	<i>3-12 times</i>		2
	<i>At least weekly</i>		3
<i>Pursuing a hobby in the last 3 months</i>	<i>Never</i>		0
	<i>1-2 times</i>		1
	<i>3-12 times</i>		2
	<i>At least weekly</i>		3
<i>Driving a car or going on a bus in the last 3 months</i>	<i>Never</i>		0
	<i>1-2 times</i>		1
	<i>3-12 times</i>		3
	<i>At least weekly</i>		4
<i>An organised trip or day out in the last 6 months</i>	<i>Never</i>		0
	<i>1-2 times</i>		1
	<i>3-12 times</i>		2
	<i>At least twice weekly</i>		3
<i>Gardening in the last 6 months</i>	<i>Never</i>		0
	<i>Light</i>		1
	<i>Moderate</i>		2
	<i>All necessary</i>		3
<i>Household or car maintenance in the last 6 months</i>	<i>Never</i>		0
	<i>Light</i>		1
	<i>Moderate</i>		2
	<i>All necessary</i>		3
<i>Reading books in the last 6 months</i>	<i>None</i>		0
	<i>One in 6 months</i>		1
	<i>Less than one in a fortnight</i>		2
	<i>More than one each fortnight</i>		3
<i>Paid employment in the last 6 months</i>	<i>None</i>		0
	<i>Up to 10 hours a week</i>		1
	<i>10-30 hours a week</i>		2
	<i>Over 30 hours a week</i>		3

ASSESSMENT BECK DEPRESSION INVENTORY

I'm now going to ask you some questions about how you feel inside. I'm going to read four statements and I would like you to tell me which one applies to you during today. I am also going to give you a form with the statements on so that you can follow the questions.

Give pre-printed list of statements.

The first question can be delivered as an example, and then repeated for assessment. On completion check that the patient has not scored the same for each series of statements. If they have please explain that it is highly unlikely that people experience every issue with the same degree of severity, and that they may like to reconsider some of their responses.

I do not feel sad		0
I feel sad		1
I'm sad all the time and can't snap out of it		2
I am so sad or unhappy that I can't stand it		3

I am not particularly discouraged about the future		0
I feel discouraged about the future		1
I feel I have nothing to look forward to		2
I feel that the future is hopeless and that things cannot improve		3

I do not feel like a failure		0
I feel that I have failed more than the average person		1
As I look back on my life all I can see is a lot of failures		2
I feel that I am a complete failure as a person		3

I get as much pleasure as I ever did from things I enjoy		0
I don't enjoy things as much as I used to		1
I get very little pleasure from the things I used to enjoy		2
I can't get any pleasure from the things I used to enjoy		3

I don't feel particularly guilty		0
I feel guilty over many things I have done or should have done		1
I feel quite guilty most of the time		2
I feel guilty all the time		3

I don't feel I am being punished		0
I feel I may be punished		1
I expect to be punished		2
I feel I am being punished		3

I feel the same about myself as ever		0
I have lost confidence in myself		1
I am disappointed in myself		2
I dislike myself		3

I don't criticise or blame myself more than usual		0
I am more critical of myself than I used to be		1
I criticise myself for all of my faults		2
I blame myself for everything bad that happens		3

I don't have any thoughts of harming myself		0
I have thoughts of harming myself, but I would not carry them out		1
I would like to harm myself		2
I would harm myself if I had the chance		3

PLEASE NOTE: If the patient's response scores 2 or 3 please refer to the protocol at the beginning of the booklet. Please note on here the details of any referrals made / to be made, along with the patient's signature:

I don't cry anymore than usual		0
I cry now more than I used to		1
I cry over every little thing		2
I feel like crying, but I can't		3

I am no more restless or wound up than usual		0
I feel more restless or wound up than usual		1
I am so restless or agitated that it's hard to stay still		2
I am so restless or agitated that I have to keep doing something		3

I have not lost interest in other people or activities		0
I am less interested in other people or things than I used to be		1
I have lost most of my interest in other people or things		2
It's hard to get interested in anything		3

I make decisions about as well as ever		0
I find it more difficult to make decisions than usual		1
I have much greater difficulty in making decisions than I used to		2
I have trouble making any decisions		3

I do not feel I am worthless		0
I don't consider myself as worthwhile and useful as I used to		1
I feel more worthless as compared to other people		2
I feel utterly worthless		3

I have as much energy as ever		0
I have less energy than I used to have		1
I don't have enough energy to do very much		2
I don't have enough energy to do anything		3

I can sleep as well as usual		0
I don't sleep as well as I used to		1
I wake up a couple of hours earlier and can't get back to sleep		2

I wake up several hours earlier and can't get back to sleep		3
I am no more irritable than usual		0
I am more irritable than usual		1
I am much more irritable than usual		2
I am irritable all the time		3
My appetite is no different than it used to be		0
My appetite is not as good as it used to be		1
My appetite is much worse now		2
I have no appetite at all anymore		3
I can concentrate as well as ever		0
I can't concentrate as well as usual		1
It's hard to keep my mind on anything for very long		2
I find I can't concentrate on anything		3
I am no more tired or fatigued than usual		0
I get more tired or fatigued more easily than usual		1
I am too tired or fatigued to do a lot of the things I used to do		2
I am too tired or fatigued to do most of the things I used to do		3
I have not noticed any recent change in my interest in sex		0
I am less interested in sex than I used to be		1
I am much less interested in sex now		2
I have lost interest in sex completely		3

INTERVIEW CLOSURE

These questions complete the interview. Can I thank you / you both for the time you have given us to help with our studies. Your contribution is extremely useful and will help us in our work. This is the first / second interview so we will / will not be contacting you again.

**PLEASE ENSURE THAT ALL INFORMATION IS COLLATED,
INCLUDING THE CAREGIVER STRAIN INDEX.**

ASSESSMENT - CAREGIVER INDEX

The following questionnaire should be applied to the patient's principal main carer (family member). Insert patient's Christian name for X.

This section should be completed in **PRIVACY** away from the patient

I am going to read a list of things that other people have found difficult in helping out after somebody comes home from hospital.

Could you tell me if any of these apply to you?

<i>tick the box</i>	YES	NO
Sleeping is disturbed, for example if X is in and out of bed or needs help with something		
It is inconvenient as helping X takes so much time		
It is a physical strain as you do a lot of lifting or bending		
It is confining, because helping out restricts your free time		
There have been family adjustments, because your routines have been disrupted		
There have been changes in your own personal plans, for example you've had to cancel a planned outing		
There have other demands on your time, for example from other family members		
You've needed to make emotional adjustments because of for example severe rows		
Do you find that the things you have to do to help X cause you some upset (for example dealing with incontinence)		
It is upsetting to find that X has changed so much from his/her former self		
There have been adjustments at work, because for example you have had to take time off work		
It is a financial strain		
Feeling completely overwhelmed because of worry about X		
TOTAL		

Appendix 7

Trial Membership Form

Name	
------	--

Address	
---------	--

Telephone	
-----------	--

Next of Kin	
-------------	--

Next of Kin Telephone	
-----------------------	--

GP	
----	--

GP Telephone	
--------------	--

Date of Admission to Trial	
----------------------------	--

Assessment 1

Due		Completed	
-----	--	-----------	--

Assessment 2

Due		Completed	
-----	--	-----------	--

Booked in diary?	
------------------	--

Hospital	
----------	--

Date of Admission	
-------------------	--

Date of Discharge	
-------------------	--

Length of Stay	
----------------	--

Assessment Notes	
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Randomisation Guess	Control		Experimental	
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Appendix 8

Trial Data Analysis Plan

Analysis Plan

Analysis Stage	Description
Baseline	Descriptive statistics for control and experimental group patients (indicators of central tendency and variation, or proportions). Although significance tests will be performed to check the effectiveness of the randomisation strategy, the data will be displayed without significance tests (Pocock, 1983).
Process factors	<p>A between-group comparison of the following process factors will be undertaken:</p> <ul style="list-style-type: none"> • Length of stay • Place of domicile at measurement point • Profile of services received by individual patients in the trial <p>Comparisons will be tested by the t-test or the Chi-square test where appropriate.</p>
Key outcome variables	<p>Between-group comparisons will be made for scores on each outcome assessment tool as follows:</p> <ul style="list-style-type: none"> • Nottingham Health Profile (total and sub-sections) • Bartel Index • Frenchay Activities Index • Beck Depression Inventory • Caregiver Strain Index <p>An intention to treat approach to the analysis of data will be adopted where all available data will be analysed. Separate tests will be completed for 3 and 12 month data using the Mann Whitney U test. A comparison of the difference in scores between measurement points will also be undertaken, again using the Mann Whitney U test, if respective correlation co-efficients are greater than 0.5 (Matthews, 2000). In addition, a mean and confidence interval for the Nottingham Health Profile total score will be reported as the primary outcome variable for the purposes of interpretation.</p>
Sensitivity Analysis	<p>Previous analyses will be repeated as follows:</p> <ul style="list-style-type: none"> • Substitution of extreme scores for patients who have died • Carrying over scores from previous measure points • Substituting group measures of central tendency for missing data <p>to explore the impact of missing data (Hollis & Campbell, 1999; Shih, 2002).</p>
Detailed study of experimental group	A correlational analysis of the intensity of the trial intervention with the Nottingham Health Profile as the primary outcome variable will complete the planned comparisons. The Spearman's rho correlation co-efficient will be used.

An exploration of the stroke co-ordinator role

CHRISTOPHER R. BURTON BN, RGN

Lecturer, Department of Primary and Community Nursing, University of Central Lancashire,
Greenbank Building, Preston PR1 2HE, UK

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Summary

- Although there is knowledge of the substantial benefits of collaborative approaches to stroke rehabilitation, information on alternative management strategies is sparse.
- This paper describes an exploratory survey, undertaken in the north-west of England, to highlight features of the stroke co-ordinator role.
- The role is explored in terms of rehabilitation management and service development. Some strategies to support practitioners in the role, and areas for role development, are suggested.

Keywords: networking, rehabilitation nursing, role development, stroke co-ordinator.

Introduction

Stroke can have a catastrophic impact on an individual, with a wide range of far-reaching physical, psychological and social sequelae. The costs, financial and otherwise, to individuals, carers, and health and social care facilities, associated with stroke, are widely considered to be high. It is perhaps unsurprising that the management of stroke has consistently been targeted by national health strategies aimed at decreasing the national and individual burden of ill-health (DoH 1992; DoH 1997a).

After the initial disease onset, stroke services are geared to rehabilitative care and therapy designed to restore independence and develop coping skills and strategies in stroke sufferers and their carers (Nolan *et al.*, 1997). Rehabilitation, by its very nature, requires the input of a range of health care professional groups, including medicine, nursing, physiotherapy, occupational therapy, speech therapy and clinical psychology. The multidisciplinary delivery of rehabilitation requires careful management and co-ordination to ensure that information is

shared between professional groups, and that therapy is appropriate for individual patients.

The effectiveness of co-ordinated rehabilitation in reducing stroke-associated mortality and morbidity has received considerable attention in recent years. The results of systematic reviews of high quality research evidence demonstrate clearly the benefits of service co-ordination (Stroke Unit Trialists Collaboration, 1997).

There are, however, a range of co-ordination strategies to be found in both practice and the rehabilitation literature, including 'ward rounds' and 'case conferences', multidisciplinary care pathways (New *et al.*, 1995), stroke teams (Webb *et al.*, 1995), stroke units (Gibbon, 1993; O'Connor, 1996) and the stroke co-ordinator (Barnes & Lee, 1995). Our knowledge of the relative merits of these different strategies, and the stroke co-ordinator in particular, is, however, limited.

The plethora of new roles in nursing, and variation in these roles, has been highlighted by a Department of Health funded study, the ENRiP project (Vaughan & Furlong, 1997; Read, 1998). The project is being under-

taken by the School of Health and Related Research (SCHARR) at the University of Sheffield, the School for Policy Studies at the University of Bristol and the King's Fund Nursing Development Programme. This three-phase study has attempted to identify the nature of new nursing roles, how these roles function in terms of effectiveness and acceptability, and their statutory, professional, managerial and educational implications. Clarity in the development of the nursing role, demonstrated by detailed description and appraisal in the literature, is required if the potential impact of this role on patients' experiences of health care is to be explored.

Literature review

Although considerable evidence of the effectiveness of co-ordination of stroke services in improving stroke patient outcome exists, how co-ordination is achieved is only superficially considered in the literature. For example, a systematic review and meta-analysis of stroke units included studies that evaluated both multidisciplinary stroke teams and dedicated, geographically defined units (Langhorne *et al.*, 1993). As a group, the trials included in the meta-analysis demonstrate that co-ordination is beneficial in facilitating positive patient outcomes. The heterogeneity of individual trials, however, does little to develop understanding of the meaning of effective co-ordination in clinical practice.

Co-ordination of services is often seen as an intrinsic part of the nursing role in stroke rehabilitation (O'Connor, 1993). This appears, however, predominantly concerned with orchestration of multiprofessional input whilst the patient is in hospital, and co-ordinating discharge arrangements. Co-ordination is also seen as only part of the nursing contribution, and is undertaken alongside other, more 'hands-on', roles. The most recent systematic review of the nursing role in stroke rehabilitation failed to identify an explicit role of the nurse as stroke co-ordinator; however, scope for development in this area was highlighted (Nolan *et al.*, 1997).

The management of stroke is complicated by the fact that not all people who have had a stroke are admitted to hospital: there appears to be a wide range of reasons why someone is admitted or not, including physician preference (Ebrahim *et al.*, 1987). Where patients are not admitted, it is perhaps even more important that effective strategies in managing the care of stroke patients are adopted.

One study which examined this issue described the role of a stroke liaison officer (Barnes & Lee, 1995). The remit of this role was to co-ordinate and plan services for stroke

patients in hospital and the community, and to act as a focal point for communication between professionals and the patient and carers. The professional background of this officer was occupational therapy.

The number of professional groups providing a component of the total rehabilitation package a patient receives, in whatever location, may be extensive. A team approach to the delivery of rehabilitation can be managed in a number of ways, including the introduction of 'unifying' tools, such as care pathways. These are multidisciplinary documents which specify usual care for patients, usually in the same diagnostic group, with an explicit time-frame which spells out when particular interventions should be implemented (Johnson, 1997). Their purpose is to aid communication, prevent duplication, and ease the patient through the rehabilitation experience. Although a relatively recent innovation in health care, the literature demonstrates that care pathways in stroke rehabilitation are primarily concerned with inpatient rehabilitation and discharge (New *et al.*, 1995).

Any strategy for facilitating co-ordination must include an element of leadership to ensure that patient care remains on course, and that responsibilities are apparent and visible within the patient's total care package. The predominant professional group that has assumed this role has been the doctors. Certainly, what is required of the role is an insider knowledge of stroke and its consequences, and the environment in which stroke services operate. These criteria are not the sole domain of any one professional group. What is also required, however, is interaction with the patient and carer that is underpinned by an appreciation of the physical, emotional and social consequences of stroke. This can ensure that services offered are congruent with the full range of patient needs. An alternative approach to the management of the rehabilitation team is the role of stroke co-ordinator. Little description of the role, however, is available in the professional literature.

RESEARCH AIM

This study aimed to explore and describe the features of the stroke co-ordinator role, as practised in the north-west of England.

Methodology

A survey approach was adopted for the study, using a questionnaire composed chiefly of open-ended questions (Robson, 1993). The tool consisted of four sections:

- demographic details and operational description of the role;
- in-depth analysis of perceptions of the role;
- personal targets for the role;
- support required for the role.

Although data from the survey were analysed and reported anonymously, respondents were identified to facilitate networking. A directory was constructed from the sampling frame to be mailed to all participants and regional NIIS trusts.

SAMPLE

All acute and community NIIS trusts in the north-west region of England were contacted by letter, and asked to nominate any member of their staff whose remit included co-ordination of stroke services or management of stroke patients.

Each nominated individual was then sent a copy of the questionnaire, with a covering letter outlining the purposes of the study. For those individuals who did not return a questionnaire within four weeks, a further questionnaire and letter were sent. To enhance the validity of the sampling frame, participants were also asked to nominate any other professionals who were acting in a similar role.

Data analysis

All data were entered on to personal computer for analysis. A total of 12 individuals were identified as having a remit in stroke co-ordination by 92% of the trusts within the region. From those 12 individuals nominated, a total of nine completed questionnaires were returned, a response rate of 75%. Respondents failed to identify any further potential participants who were not in the original sample.

Findings

All respondents had a professional background in nursing, with most possessing post-basic professional qualifications. A range of job titles was used, including stroke co-ordinator, clinical co-ordinator, stroke team leader and stroke rehabilitation specialist nurse. Seven respondents were working in an acute NIIS trust, the remaining two in integrated acute and community trusts.

THE STROKE CO-ORDINATOR ROLE

The most striking finding about the stroke co-ordinator role itself was the variation and diversity of activities that

the role encompassed. Initially respondents were asked to describe the key areas of their role, and two broad themes were identified in the data. All respondents identified multidisciplinary working as central to their role. The second theme related to the development of stroke services. Both themes, however, incorporated a range of key areas (Table 1).

The multidisciplinary role of stroke co-ordinators in the sample included two key areas: liaison, and ward rounds or case conferences (Table 2). The key purpose of liaison appeared to be facilitation of access to rehabilitation services. This activity was highlighted by all respondents, who highlighted the importance of activities like 'patient tracking' and 'making referrals for inpatient rehabilitation'. For all respondents, the purpose of these activities was to ensure that all stroke patients within their organization, whether in a rehabilitation unit or not, had access to multidisciplinary rehabilitation services. This was particularly important for co-ordinators in organizations where there was no specific stroke rehabilitation unit, and where patients admitted with a stroke could be found on a variety of hospital wards. Another key purpose of liaison appeared to be planning discharge arrangements for patients, ensuring that support and continuing care services were in place for patients and their families.

Stroke co-ordinators appeared to play an important part in the operational management of multidisciplinary activity. This was organized either through case conferences or ward rounds. Varying degrees of involvement were reported by the sample, with five co-ordinators frequently taking on a 'chairperson' role in case conferences. A key activity in these meetings was to provide a focal point for communication between professional groups, and to communicate with the patient and family.

The range of activities that co-ordinators undertook in relation to service development was extremely varied (Table 3), and appeared to reflect the organizational needs of the stroke service, and the structural arrangements of their role. For those whose remit incorporated hands-on clinical activity as part of the nursing team, supervision, support and education of staff appeared to be important. All sampled stroke co-ordinators detailed specific activities

Table 1 Key areas of the stroke co-ordinator role

Multi-disciplinary working	Stroke service development
Liaison	Nursing supervision
Communication	Staff education
Case conferences	Practice development
Ward rounds	Service development

Table 2 The stroke co-ordinator's role in multidisciplinary working

Range	Activity
Liaison	Facilitation of access to rehabilitation services, patient tracking Making referrals for inpatient rehabilitation and discharge
Case conferences and ward rounds	Communication, involvement, leadership, advocacy

Table 3 The stroke co-ordinator's role in developing stroke services

Range	Activity
Nursing supervision	Involvement in quality assurance initiatives
Staff education	Staff teaching (specific to stroke care), clinical role modelling
Practice development	Clinical supervision, supporting change in practice
Service development	Promoting links between the hospital and community Facilitating the development of stroke services

that were designed to improve the utility of stroke rehabilitation services, either by re-focusing the service on stroke (in generic rehabilitation units), promoting links with community provider teams and voluntary support agencies, or by acting in the capacity of 'facilitator' or 'negotiator' for service development.

Respondents were also asked to provide a breakdown of the amount of time spent in core activities during an average week. The majority of co-ordinators' time was occupied with clinical practice (mean: 23.8 h per week; range: 16–30 h), where clinical practice included all aspects of interaction with patients and carers and the multidisciplinary team.

Five respondents performed their stroke co-ordinator role alongside other roles, principally rostered 'hands-on' practice within the hospital environment as part of the nursing team. Seven respondents had managerial responsibility for a specific part of inpatient services, which accounted for a significant proportion of their time (mean: 8.5 h per week; range: 2–12 h). For six this related to operational management of the rehabilitation unit itself, including staffing issues, and maintenance of the unit environment and resources.

A relatively small proportion of respondents' time was spent on maintaining individual professional development (mean: 2.4 h per week; range: 0–4 h).

REQUIREMENTS FOR THE ROLE

Respondents identified a range of requirements for the stroke co-ordinator role, including:

- an in-depth knowledge of stroke;
- clinical credibility, including experience of working with stroke patients;
- a holistic attitude to patient care;
- determination and commitment;
- empathy;
- a willingness to take risks;
- management experience;
- research and development experience;
- targets for the role.

A range of personal targets or objectives of the role was identified, which fell into three broad areas: service development, the role itself, and research and development. With respect to development of services, objectives were classified in terms of both structure and process aspects of the service (Donabedian, 1992).

In terms of structure, expansion of links to the voluntary sector was identified by three respondents, whilst two stroke co-ordinators identified development of a dedicated stroke unit as a key priority. Both of these respondents were working in generic rehabilitation units, which catered for patients requiring rehabilitation for a variety of reasons, for example after surgery. Process issues identified included development of teaching packages for patients and carers, development of multidisciplinary care pathways, and development of stroke assessment tools.

Development of the role was highlighted by respondents who wished to develop networks, to enable sharing of ideas and innovations in practice, to disseminate research and evidence of best practice in stroke rehabilitation, and to facilitate problem-solving amongst peers. Two respondents identified development of stroke registers as an objective for their role, in order to facilitate audit, patient tracking and research activity.

SUPPORT REQUIRED FOR THE ROLE

Given that the stroke co-ordinator role is a relatively recent development in health care, support of practitioners taking on this development is essential. Respondents were asked to describe the support they felt was required for the role. Four themes were identified from responses:

- support from multidisciplinary colleagues;
- support from other stroke co-ordinators;
- management support;
- freedom to take risks.

Furlong & Glover (1998) maintain that support given to nursing roles, such as the stroke co-ordinator, by senior medical colleagues, is crucial to the development of such roles. It is proposed that this can often be mediated by the estimation held for the individual nurse by the consultant. Whilst this was not a key finding from this survey, the support of multidisciplinary colleagues was cited by all respondents as crucial to the successful operation of the role.

Formal links with an educational institution, for example through specific courses or joint working, were not highlighted as being essential to the role. The data suggested that individuals sought support and advice from peers either within their own clinical area, or from other stroke co-ordinators in other organizations.

Discussion

Generalizability of the findings is restricted by limitations of both the method and the sampling frame used in the study. The aim of the study, however, was to explore and describe features of the role in practice to develop understanding and facilitate evaluation. A number of important features of the role were identified.

ROLE STRUCTURE

There appears to be little consistency in the structure of the stroke co-ordinator role: it appears to be performed either as a role in itself, or in tandem with other roles. A number of respondents were nurses in clinical practice who had been allocated regular time to perform the role outside the constraints of rostered practice. For those nurses who performed the role as a supplementary activity, this was rarely formalized in a job description. This situation may reflect either a role in evolution, or a lack of importance attached to the role on the part of health care trusts.

The stroke co-ordinator role appears to concentrate on two key areas: co-ordination of multidisciplinary care, and development of services available to stroke patients and their carers. Co-ordination relates to a range of activities, including patient referral, tracking stroke patients within the service, participating in and leading multidisciplinary case review, and arranging the patient's discharge.

Interestingly, there was little evidence of direct involvement with patients and carers following discharge.

Transition from hospital to home has been reported to be a time of extreme uncertainty for stroke patients and their carers, requiring the application of developing coping skills to new surroundings (Doolittle, 1991). Although the stroke co-ordinator has the opportunity to ensure that services offered by others are in place for the patient on discharge, the unique knowledge of the patient developed by the co-ordinator and clinical team during hospitalization is potentially lost.

Problems that stroke patients and their carers can face relate very much to the short, medium and long-term. The effects of a stroke can pervade all aspects of an individual's life, and will require dynamic and alternative coping strategies. Traditionally rehabilitation has concentrated on developing physical independence: although evidence for withdrawal of professional rehabilitative input is ambiguous (Barnes & Lee, 1995), the patient has the potential to improve from rehabilitation after discharge from an inpatient unit. Similarly this input will be multidisciplinary in nature, and will require co-ordination. Whilst study participants highlighted the potential for developing the links between acute and community care, there appears to be limited capacity for the provision of an overarching perspective in stroke co-ordination that spans the entire course of recovery from stroke. Such a strategy might be highly effective in reducing the anxiety associated with hospital discharge, and maintaining therapeutic relationships in order to plan and implement effective care, support and teaching into the long term.

PROFESSIONAL BACKGROUND

Although all the study participants had a nursing background, it does not necessarily follow that nurses are best placed to act in a stroke co-ordinator role. There are, however, a number of distinct advantages to suggest that nurses are well suited to the role. Nurses have a unique position in the delivery of stroke patient care: as a professional group they have 24-hour contact with patients during hospitalization (Waters, 1987). As a consequence, they can be privy to sensitive personal information, fears and anxieties which can shape the delivery of care and effective rehabilitation. The philosophies which underpin nursing practice, although eclectic, place great importance on addressing the holistic aspects of care and therapy, and implementing humanistic approaches to delivery. This philosophy is required to ensure that rehabilitation is appropriate, acceptable and centred on individual patient needs.

NETWORKING

Although members of a multidisciplinary team, there is considerable potential for stroke co-ordinators to experience isolation, particularly in terms of obtaining support and professional development. Networking has been described as the process of linking with peers, either within or across institutional boundaries, to facilitate support, professional development, sharing information on best practice, and disseminating innovation (Wright *et al.*, 1997).

The lack of description of the stroke co-ordinator role within the literature presents the individual with the opportunity to develop in a number of ways. This may, to some extent, be witnessed in the findings of this survey. It is essential, however, that the role develops in a manner that is consistent with the developing evidence-base in stroke rehabilitation. Although targeted in health policy (DoH, 1997b), mechanisms to support the development of evidence-based health care are patchy (Newman *et al.*, 1998). Access to up-to-date information, via electronic databases (for example the Cochrane Database, MEDLINE and CINAHL) and the internet, is not always available. Given this situation, it is essential that there are opportunities for practitioners to support each other, thereby pooling information resources, to develop best practice which is consistently available to stroke patients and their families.

Although the stroke co-ordinator role may be in evolution, it will be essential for it to be evaluated in terms of its ability to improve the experience of rehabilitation, and ultimately patient outcomes. Where information on best practice is available, this must be shared and implemented consistently.

Conclusion

Fragmentation in service delivery has the capacity to cause frustration and anxiety, so reducing the capacity an individual has to cope with stroke (Doolittle, 1991). Advocacy groups have persistently highlighted the prevalence and negative impact of fragmentation in stroke services (Stroke Association, 1994, 1996). The benefits of well co-ordinated stroke rehabilitation programmes have been demonstrated, in terms of reducing both the mortality and morbidity associated with stroke. Our understanding and knowledge of effective co-ordination strategies remains, however, limited.

This exploratory survey has described some features of the stroke co-ordinator role as practised in the north-west of England. The role has been demonstrated to be concerned with both co-ordination of the delivery of multidisciplinary rehabilitative therapy, and development

of services on offer to patients. The role appears to be particularly prominent in orchestrating inpatient rehabilitation, and planning for patient discharge.

The role of stroke co-ordinator is a relatively new development: practitioners in the role will consequently require considerable support. Stroke is a complex clinical condition to manage, and stroke services can operate in a range of environments. This can be witnessed in the variability of role structure within the regional sample. Although services need to be flexible to meet the plethora of needs associated with stroke, provision must be consistent with current evidence of clinical effectiveness.

The infancy and structure of the stroke co-ordinator role do have the potential to predispose to professional isolation, so reducing opportunities for supported development and access to up-to-date information on best practice. Networking may be a strategy for stroke co-ordinators who wish to develop their role and the services they offer to patients and their carers. It will be essential, however, that networks are capable of supporting best practice by, for example, linking with research and development centres within higher education, or national initiatives on clinical effectiveness.

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A description of the nursing role in stroke rehabilitation

Christopher R. Burton BN RGN

Lecturer, Department of Primary and Community Nursing,
University of Central Lancashire, Preston, England

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A description of the nursing role in stroke rehabilitation

A theoretical description of the nursing role in stroke rehabilitation remains elusive in the literature. The United Kingdom strategy for health service development will increasingly require nurses from all clinical specialities to collaborate with other health care professionals and stakeholders to evaluate the services they provide. In stroke rehabilitation, an understanding of the contribution that nursing makes is essential, if that collaboration is to be effective. This paper details a study undertaken to describe the nature of the nursing role in stroke rehabilitation, and the factors that shape this role. A reflective enquiry was used to enable the collection of data grounded in the realities of clinical practice. Study participants were qualified nursing staff ($n = 13$) working in a rehabilitation unit in the north-west of England. A total of 35 in-depth reflections were obtained for analysis. Three role categories were identified in the data: the nurse as care giver, facilitator of personal recovery and care manager. Sub-categories of nursing intervention were identified within each category, together with anticipated outcomes and contextual features that shaped the category. The results of the study were verified by a purposive sample of nursing staff from the rehabilitation unit.

Keywords: health services research, nursing role, professional development, stroke rehabilitation, reflective enquiry

INTRODUCTION

The recent United Kingdom (UK) National Health Service (NHS) white paper highlights the potential that nursing has to bring to the development of health services (Department of Health 1997). Increasingly nurses will collaborate with other health care stakeholders, including other professional groups, care sectors and patients, to develop and evaluate their contribution to health care provision. Effective collaboration has to be built on the sharing of knowledge and philosophies, with negotiation underpinned by the recognition of the value and practical

knowledge of all contributors. The ability of nursing to articulate its contribution to health care is paramount if the development and evaluation of health care is to achieve its aim: a fairer, appropriate and more effective health service for all (Department of Health 1997). Although these issues are pertinent to all fields of nursing, the necessary understanding and agreement on the nursing contribution in stroke rehabilitation appears to remain limited (Nolan *et al.* 1997).

LITERATURE REVIEW

An early paper containing the viewpoint of the nurse as *rehabilitator par excellence* (Henderson 1980) appears to contain all the major themes that feature in the debate surrounding the nursing role in stroke rehabilitation. This

Correspondence: Lecturer, Department of Primary and Community Nursing, University of Central Lancashire, Greenbank Building, Preston PR1 2HE, England. E-mail: c.burton@uclan.ac.uk

debate appears to continue to the present day (Nolan *et al.* 1997). Henderson's (1980) paper addresses a wider agenda than rehabilitation alone: the combination and potential conflict between the technical or scientific, and humanistic aspects of nursing care. The reference to rehabilitation appears to capture the central features of humanistic practice that should be, according to Henderson, at the centre of nursing practice in all clinical fields: the ability to develop and use a deep understanding and empathy of an individual's world to promote effective and consistent care.

A description of the rehabilitation role of nursing in the literature has recently been summarized in a systematic review commissioned by the English National Board for Nursing, Midwifery and Health Visiting (ENB) (Nolan *et al.* 1997). The review was not specific to stroke, and included a range of diagnostic groups where rehabilitation was thought to be a significant feature of nursing care. The review identified five domains of clinical practice that characterize the nursing role in rehabilitation:

- physical well-being (including care of the skin, nutrition and hygiene);
- a specialist role in continence and care of the skin (Waters & Luker 1996);
- creating and sustaining an environment for rehabilitation;
- reinforcing the input of other professional groups; and
- a 24-hour presence (Waters 1987).

Although the review was extensive, little information is given on the quality of individual studies identified in the search strategy. Indeed the lack of empirical evidence to support these domains is evident. The breadth of the review necessitated a low proportion of studies being obtained for critical appraisal. As a consequence, perhaps, the review focused usefully on areas of potential for the development of the nursing role in rehabilitation, rather than identifying the role itself. The review does, however, demonstrate the complexity and multiplicity of perspectives, foci, processes and roles that nurses fulfil or address in the delivery of rehabilitative care.

Whilst general agreement of the nursing role as manager or co-ordinator of multidisciplinary rehabilitation appears to be developing (O'Connor 1993), the lack of a research base for specific nursing interventions demonstrates that a therapeutic role for nursing remains elusive. However, the emergence of nursing research that seeks to understand the human response to stroke (Doolittle 1992, Folden 1994) suggests that the development of patient and carer coping strategies is likely to be a key area for nursing practice development. For example, Catanzaro (1993) maintains that the goal of rehabilitation nursing is to help individuals with a disability to return to optimal effectiveness in daily living, and that cumulative abilities in discrete activities of living enable participation in the wider social world. Consequently, rehabilitation is

focused on the social processes of adaptation and negotiation between the individual and their environment.

The nurse in rehabilitation then has a therapeutic role concerned with facilitation of this social process to enhance the human response to a debilitating illness such as stroke. Whilst this description of rehabilitation is useful in drawing attention to the wider aspects of stroke recovery, the application of a social model of rehabilitation to the prevalent pattern of stroke nursing services may be problematical. Nurses tend to provide rehabilitative interventions with stroke patients in institutional care settings (Gibbon 1994), which have only limited capacity to reflect the realities of the social environment which patients come from, and return to.

From a direct clinical perspective, Gibbon & Little (1995) attempted to develop nursing practice for stroke patients in hospital using action research. Their study required a frank analysis of baseline nursing practice from which the team could move forward. A profile of study interventions were tailor-made to facilitate the development of stroke patient care from the baseline, including a tutorial programme, nursing documentation system, clinical guidelines, and communication strategy to facilitate multidisciplinary collaboration.

Tensions appear to exist between active therapy and care components of nursing care, despite evidence of the clinical effectiveness of early activation programmes (Stroke Unit Trialists Collaboration 1997). This issue is mirrored by the findings of a recent and comprehensive literature review specific to stroke (Kirkevold 1997). The review described two dimensions of the nursing role in stroke rehabilitation: the provision and management of the context for effective rehabilitation, and the provision of specific therapeutic interventions. Whilst reviews of the literature can be beneficial in determining current professional knowledge, their quality depends on the validity of the individual studies that have been included. This issue does not appear to be addressed in the review.

Kirkevold's (1997) review was, however, underpinned by an earlier study of experienced nurses working in a specialized stroke unit (Kirkevold 1992). Interviews and observation identified four therapeutic functions or domains in stroke rehabilitation nursing:

- an interpretive function that helped patients and families understand the implications of stroke;
- a consoling function in providing emotional support;
- a maintenance function to ensure that patients attain the best possible 'state' for therapy; and
- the integration or translation of therapy, where nurses help patients to assimilate discrete skills or activities learned in formal therapy into meaningful self-care or social activities.

The review attempted to validate these four functions by exploration of their congruence to the research base.

Stroke rehabilitation studies published between 1989 and 1995 were identified and mapped according to their clinical focus. The review demonstrated that there is a dearth of literature available to support the validity of this framework, and that there is a pressing need for clarification of the nursing role in stroke rehabilitation.

THE STUDY

Aim

This study aimed to explore and describe nursing practice in stroke rehabilitation.

Methodology

A qualitative approach was adopted, to enable a rich description that would make sense of the clinical realities of the nursing role (Morse & Field 1995).

The key tool for data collection was reflection, which refers to the process of subjecting decision-making to scrutiny using established theory, where possible, as a benchmark for comparison. It has been proposed that this enables the surfacing of knowledge that evolves from experience in practice (Heath 1998). It was hoped that by adopting this approach, the data would be more reflective of the individual norms and values that precipitated action.

Location and participants

The research site was a 24-bed rehabilitation unit in a district general hospital in the north-west of England. The unit caters predominantly for people who have suffered a stroke, but also for people requiring rehabilitation after some surgical procedures, for example hip replacements. The unit has close links with a day hospital, and has a range of multidisciplinary professionals formally attached to the unit.

The unit is managed by a rehabilitation manager (a senior nurse), supported by a senior staff nurse. Nursing care is organized around a team structure, each team having particular responsibility for a 'bay' of between six and eight patients. Each team is led by a registered staff nurse, supported by a number of staff and enrolled nurses, and unqualified staff (Table 1). The mix of staff at the time of the study was 60% qualified and 40% unqualified staff who worked as nursing auxiliaries or health care assistants. The difference between these two groups of staff was contractual in nature, both working in a supportive capacity to qualified nurses. The study sample consisted of all qualified nursing staff ($n = 13$) working in the rehabilitation unit at the research site.

Table 1 Nursing profile of rehabilitation unit

Job title	Number of staff	Mean years in rehabilitation
Rehabilitation manager	1	4.8
Senior staff nurse	2	3.1
Staff nurse (team leader)	3	2.3
Staff nurse	5	3.8
Enrolled nurse	2	6.2

Multidisciplinary profile

The rehabilitation unit was headed by a consultant physician, supported by a small team of junior doctors. A physiotherapist and occupational therapist were attached to the unit, and provided a number of dedicated sessions to the patients on the unit. Multi-disciplinary care was facilitated by case conferences: these occurred weekly and were attended by the full range of professionals who had an input into a particular patient's care. Patients, or their carers, did not attend case conferences. Each professional group maintained their own records, although some therapists, principally physiotherapists, recorded assessments in the nursing care plans.

Data collection

Participants were supplied with proformas developed from the double loop model of reflection proposed by Greenwood (1998). After completing questions relating to biographical data, nurses were asked to describe a particular clinical incident that had been important to them. They were advised to select an issue that had occurred during their last shift in practice, so as to maximize recall. Each reflection commenced with a full description of the incident, and what else was happening around them at the time. They were asked to specify a range of outcomes that they were attempting to achieve and why the outcomes were important to themselves, the patient, the multidisciplinary team and the organization. The final questions related to alternative courses of action, and the reasons why these alternatives were not adopted. Participants were encouraged to complete a minimum of three reflections within 3 months.

Ethical considerations

Ethical approval was obtained from the hospital research ethics committee prior to commencement of the study. Participants were given a brief explanation of the purposes of the study before consent for inclusion was sought. All qualified nurses in the rehabilitation unit agreed to participate. All data are reported anonymously.

Data analysis

A total of 35 reflections were obtained for analysis. Each reflection was treated as a transcript, and was subjected to analysis using the framework advocated by Burnard (1991). Although this framework was developed specifically for interviews, the process of analysis was appropriate to the type of data generated. Initially, each reflection was read in entirety to aid 'immersion' in the data. Open codes were reviewed and condensed where possible into a coding frame of categories and sub-categories. Reflections were again reviewed using a word-processing package so that the content and context of each sub-category could be collected in separate files. Each sub-category was explored in terms of three elements: nursing activity, patient outcome and the contextual features that shaped the intervention. The coding frame was reviewed and confirmed by an independent researcher.

Verification

On completion of the study, the findings were verified using a focus group methodology (Carey 1994). A purposive sample of four nurses of different grades was drawn from the unit staff to participate in the group. Although including staff of different clinical grades and experience potentially decreases disclosure (Kreuger 1988), it was felt that representation from the nursing team was required. The group commenced with a discussion about the research methods used to act as a warm-up. The findings of the study were then presented and discussed, followed by closer scrutiny of thematic content. Focus group participants were asked to reflect on the ability of the study findings to reflect the realities of practice.

FINDINGS

Three categories that described the nursing role were identified within the data: the nurse as provider of care, facilitator of personal recovery and the manager of multi-disciplinary provision. Each category is associated with a range of anticipated patient outcomes, and consists of a number of sub-categories described in terms of nursing

interventions. A number of contextual factors are identified in the data that appear to shape nursing activity within each category.

The nurse as provider of care

Nurses tended to see themselves as the principal providers of care for stroke patients, most citing the continual presence of nurses on the rehabilitation unit as evidence for this:

We're with them all the time.

The others seem to come and go. They do their bit and seem to disappear. They don't seem to have the time. It's not always easy for us, but at least we have more opportunity because we're always there.

Three sub-categories of care, doing, providing and educating, were identified in the data (Table 2). These sub-categories related to care activities that were predominantly aimed at the completion of interventions where basic physical needs were provided for, patient safety was maintained and harm to the patient prevented. Often these activities were prescribed by other professional groups, or were related to nursing policies and procedures, and established practice regimes:

...giving (medication) to prevent further infarction.

...getting the patient comfortable.

...doing his dressing.

Importantly these activities tended not to be directly related by participants to outcomes of rehabilitation. There appeared to be a strong belief that there were a number of activities that had to be completed:

We were a bit busy that morning. I had to leave doing his dressing until after lunch. He did need it doing then [the morning]. We try to get them done and out of the way.

I just gave them the leaflet. It wasn't ideal really. I wanted to go through it with them. I decided it would be best to leave until next time when I hoped I would have a bit more time. That sort of thing happens a lot.

Table 2 Category: the nurse as care provider

Category	Outcome ranges	Sub-categories	Contextual factors that shape category
Care provider	Completion of basic requirements (including nutrition, hydration, elimination, hygiene)	Doing	Rehabilitation
	Maintenance of safety (completion of activities prescribed by others)	Providing	External pressures and constraints
	Prevention of harm	Educating	

Although these examples were reported by different nurses on different occasions, the contextual feature shared between both was the interruption of the consultant round during the activity. Other factors that affected the delivery of nursing activity in this category related to external constraints which typically concerned human and technical resource issues.

The nurse as facilitator of personal recovery

A number of nursing interventions suggested a greater degree of interaction between the patient and nurse, the key purpose of which were the development of coping strategies and the maintenance and improvement of well-being. Although some of these activities were related to specific physical activities of living, they tended to be set within a wider context:

...helping the patient to drink

I spent some time with her helping her to eat her lunch... helping her with the spoon... It might not seem that important to some nurses, but this sort of thing is what we really should be about. It's all about helping them to cope in the long term.

Four sub-categories were identified that described the nurse as a facilitator of personal recovery: helping, comforting, teaching, and working with the patient and family (Table 3). The contextual features that appeared to be associated with these activities were individual nurses' beliefs about the purpose of rehabilitation, and the relationship developed between the nurse and the patient and their families and carers. Nurses often cited the importance of a positive relationship to help patients come to terms with their stroke, and to help them move on.

Nurses recognized the important part that family and friends would play in a patient's long-term recovery:

At the end of the day...[the family]... will have to pick up the pieces. We end up looking after them as much as the patient.

Effective communication was seen as key to building relationships to facilitate the gathering of information

about social support and circumstances to mediate care planning. Recognition of the psychological sequelae of stroke in practice were particularly evident, with a high priority attached to activities that the nurses perceived to alleviate stress and anxiety, and to promote effective coping strategies:

The nurses role here is important in helping a patient come to terms with having a stroke and the fact that his/her life has not come to an end, and that there will be light at the end of the tunnel.

These activities were identified as both specific activities important in their own right, but also indirect activities that were carried out alongside other, more physical, activities:

I was putting up his feed and it was quite late. He seemed very quiet. I don't know. Just not right...how he had been. I sat with him after I finished and just held his hand. Not much really. It seemed to work. He went to sleep soon after.

Nurses also identified a range of activities that could be perceived to be the domain of other professional groups. A close partnership with, for example, the physiotherapist was highlighted, with nurses providing and facilitating much of the practice element with patients:

The physio had assessed her mobility, and I was helping her to mobilize according to the care plan.

This appeared to be a logical reaction to the structural nature of multidisciplinary work of the unit where it was perceived that the physiotherapist had only limited time available for individual patients. Nurses tended to leave the assessment of patients' mobility to the physiotherapist, but continued to work with the patient during her absence. Participants maintained that whereas the therapists worked with patients to develop micro or fine physical skills, their role was to translate these skills into physical function in activities of living:

I knew she hadn't had much practice time on her hand exercises. When I was helping her to get washed we were able to include some of those exercises in her routine.

Table 3 Category: the nurse as facilitator of personal recovery

Category	Outcome ranges	Sub-categories	Contextual factors that shape category
Facilitator of personal recovery	Maintenance and improvement of well-being (emotional and social aspects of recovery) Improved coping strategies (emotional, social and physical aspects of recovery) Improvement in activities of living (including core life skills)	Helping	Beliefs and values about nursing and rehabilitation
		Comforting	
		Teaching	External constraints and pressures
		Working with Risk taking	Willingness to take risks

The multidisciplinary input from other members of the team was structured according to a range of factors, including the number and availability of therapists. Although nurses recognized the expertise of other professional groups, there were a large number of instances where nurses were unsupported in their delivery of rehabilitation. In these instances, nurses appeared to assess the risk of the patient not receiving an assessment for some time, and instituting care based on that assessment:

The speech therapist was on holiday and he hadn't had a swallowing assessment. We couldn't leave him on a drip for days. He appeared to be able to swallow OK, I mean he wasn't coughing or anything. So we decided to try him with some fluids.

It appears that risk-taking was used to counter deficiencies in the structure of the delivery of multidisciplinary rehabilitation, to ensure that patients received what was perceived to be appropriate intervention. It appeared, however, that this action was unsupported by either formal training, or the use of formal assessment tools.

The nurse as manager of multidisciplinary provision

Nurses described a range of activities that related to the management of patients, including liaising, organizing, mediating and planning (Table 4). These activities were designed to co-ordinate the input of other health care professionals, to promote the well-being of patients and their families, and to enable smooth transitions of care for patients:

We needed to make sure the dietician saw him.

His wife was worried about [toilet facilities at home]. I knew [occupational therapist] was dealing with this, so I discussed what we were planning.

My main concern was that everything would fall into place when she went home.

Co-ordinating the multidisciplinary team on a day-to-day basis was a key aspect of patient management and involved the strategic planning of patient care. The case conference was identified as the principal process by

which important decisions regarding patient care were made. Nurses identified a range of activities in case conferences:

...sharing information with other professionals.

...acting in an advocacy role for patients.

With respect to information, nurses felt they were best placed to provide information relating to patients' general progress, coping and emotional health. Other information they provided related to the patient's home circumstances and social support. Their perception of patient advocacy related to the depth of knowledge they had developed as a result of their interaction with patients and their carers.

The case conference appeared to be a forum for sharing ideas and knowledge specific to individual patients with other members of the health care team. Nurses cited few instances where written information was shared in a formal way, for example, shared documentation systems. Whilst not necessarily having what they saw as ultimate responsibility, they had developed proactive relationships with other health care professionals, and with patients, to enable this aspect of their role:

I had spent a lot of time with [patient and family] discussing their main concerns. We talked about how things might be. I mean I have spent a lot of time [nursing stroke patients] and you get a feel for the sorts of things that bother them and how things might go in the future. It's not just the here and now, but how are they going to cope years down the line. It's important.

It's almost like they live with you. You really get to know them. We do everything with them. I mean no-one else sees or hears all that we do. That's really important when you are planning their future with them.

DISCUSSION

A reflective methodology was adopted for this enquiry in an attempt to elicit a description of nursing practice in stroke rehabilitation that was grounded in reality. The nursing role in stroke rehabilitation is, however, diffuse and complex.

The 24-hour presence of nurses for stroke patients can be responsible for the development of an environment that is conducive to rehabilitation (Waters 1987). However, the

Table 4 Category: the nurse as care manager

Category	Outcome ranges	Sub-categories	Contextual factors that shape category
Manager of multidisciplinary provision	Multidisciplinary care input Smooth transitions of care and rehabilitation Well-being of patient and family/carers Planning	Liaising Organizing Mediating	Multidisciplinary team structure and philosophy Relationship developed with patient and family/carers

structure and delivery of care may not always match this philosophy. A clear and focused analysis of what nurses are actually doing, and why, within these 24 hours is essential to develop and promote the quality and effectiveness of services available.

Waters (1994) suggested that quite often nurses *do for* a patient in rehabilitation, but that this does not necessarily help the patient to achieve independence. She cites a number of reasons why this may be so, including the structure of rehabilitative nursing care and multidisciplinary input, and beliefs about rehabilitation. To explore this issue further, however, requires an understanding of the stated goals of nursing intervention, and the external and internal factors that either precipitated a change in the desired outcome or mode of intervention.

Nurses in this study undertook a range of activities that were concerned with the provision of care to ensure that basic physical requirements were met to prevent deterioration or harm. Interestingly, the anticipated outcomes and contextual features of these activities were related to factors outside the control of nurses themselves. Rarely were they linked to the wider, daily living outcomes of rehabilitation. This finding may support the description of nursing work that has to be completed in stroke rehabilitation demonstrated by both Waters (1994) and Gibbon (1994).

Nurses appeared to value the therapeutic aspects of nursing care, and were able to describe interventions that were aimed at emotional well-being, coping skills and improvement in activities of living. This type of nursing intervention tended to be underpinned by the development of a positive relationship between the nurse and patient and family. Involving the patient in decision-making and encouraging an active participation in rehabilitation has been strongly advocated (Nordstrom 1980). Although the observable benefits of this approach to rehabilitation are difficult to determine (Hamrin & Lindmark 1990), they appear to be both desirable and necessary from a sociological viewpoint (Pollitt 1988).

Nurses tended to leave the assessment of patients' mobility to the physiotherapist, but continued to work with the patient during her absence. This supports the findings of other studies that describe the understudy role of nurses to other health care professionals in stroke rehabilitation (O'Connor 1993), and see the therapist as the expert (Waters 1994). Although some aspects of nursing role identified in this study were delivered to complete activities on behalf of the patient, a clear therapeutic function was highlighted. Nurses were able to translate the development of discrete physical skills into activities of daily living with the patient. A surprising finding was the nurses' willingness to perform aspects of services provided by other professional groups when it was perceived that the patients' potential for recovery was reduced by their unavailability. Formal training to support the nurse in these activities appeared to be absent.

O'Connor (1993) maintains that the managerial aspects of the nursing role implies the role is secondary to the roles of other professional groups, as no specific function is delineated. If, however, nurses do operate in stroke rehabilitation with an holistic awareness that is drawn, as Henderson (1980) would maintain, from 'getting inside the patient's skin', then this does imply a unique function. The nurse would indeed be in the best place to co-ordinate and mediate the contributions of other professional groups to ensure that patient progress is maintained.

A number of important features of the nursing role are evident which provide understanding and capacity for development of the nursing contribution to stroke services. The nursing role in stroke rehabilitation is fundamentally concerned with the provision of care which is technical, therapeutic and managerial in nature. This care is aimed at a range of patient outcomes that include the maintenance and improvement of health and well-being, and the development of coping strategies. Nurses appear to adopt a range of strategies to help patients achieve these outcomes dependent on a number of factors. There is a core of activities that attempt to prevent further deterioration in the patients' condition, to prevent harm, and to maintain safety, that appear to be 'done for' a patient. These actions appear to infer the patient as a passive recipient of care and rehabilitation, and tend to be rule, or policy, driven.

There is a range of activities, however, which appear to promote a partnership between the patient and nurse, where the two work together to achieve improvement and coping on the part of the patient. These activities tend to be influenced more by the perceptions and attitudes of the individual nurse. The importance of an holistic approach to the consideration of the outcomes of stroke rehabilitation has been documented (Hart 1998). The distinction was drawn between 'being' and 'doing', where performance of specific activities of living has to be placed in the context of an individual's life. Where restoration of function is the goal of rehabilitation, this tends to be approached in a reductionist manner which builds on a repertoire of discrete skills. This approach may neglect the socio-psychological importance of function as a whole. Although the outcomes specified by nurses in the sample appear to recognize the socio-psychological impact of the stroke or loss of function, more research is required that focuses on the process of goal setting with stroke sufferers and their carers.

There is considerable overlap between nurses and other health care professionals that tends to be a product of the organization of in-patient rehabilitation services. This would suggest that the development of the relationship between nursing and other professional inputs is a product of organizational management, rather than any professional development, or patient-centred approaches to rehabilitation.

Study limitations

The findings of this study, whilst an addition to the body of research, have only limited generalizability, due to the restricted location of the study. Only one rehabilitation unit was sampled. The methods employed attempted to describe nursing practice and to discern, to some degree of depth, the issues that were important in the shaping and delivery of nursing care. The findings were, however, endorsed by a representative focus group of nurses from the study site as being reflective of the realities of clinical practice.

CONCLUSION

Nursing has a key role in the provision of multidisciplinary rehabilitation to people that experience a stroke. As well as providing interventions that maintain and ensure physical integrity for recovery, nurses are able to use the knowledge and understanding of individual patients' needs they acquire through working with patients and their carers to shape the multidisciplinary rehabilitative effort. Nursing interventions that were specifically related to the outcomes of rehabilitation were characterized by the nature of the interaction between patient and nurse: a partnership to improve coping, well-being and meaningful activities of living. These interventions included shaping the contributions of other professional groups to individual patient circumstances whilst practising therapy. The fluidity of the overlap between nursing and other professional groups is, however, demonstrated when nurses expand their practice to perform interventions which normally are perceived to be the remit of others.

Nurses have the capacity to affect a great degree of change in both the quality of rehabilitation services, and the outcomes that stroke patients achieve, as a result of the quantity of interaction that they have with patients. Nurses must capitalize on this feature of their role to build on and develop new partnerships with patients and carers outside of the traditional boundaries of rehabilitation. The potential to develop new partnerships with stroke patients and their families has been highlighted in the literature (Nolan *et al.* 1997). This development would highlight the therapeutic aspects of the nursing role in stroke rehabilitation. Nurses would then be able to use the knowledge and experience they develop by working with individual patients to greater advantage to help patients to make sense of and cope with a stroke in the long term.

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Living with stroke: a phenomenological study

Christopher R. Burton PGCertHE BN RGN

Senior Lecturer, Department of Primary and Community Nursing,
University of Central Lancashire, Preston, England

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Living with stroke: a phenomenological study

Understanding how stroke sufferers experience their stroke and recovery is essential if the development of rehabilitation services is to be effective and appropriate. Previous research in this area has tended to be either cross-sectional or with a limited amount of informant follow-up, and consequently has limited utility. This paper describes a study underpinned by a phenomenological approach, which tracked the experiences of six patients admitted to a rehabilitation unit in the north-west of England. Informants were followed for at least 12 months after stroke, and a total of 73 interviews were undertaken during the study. The data demonstrate that recovery from stroke involved restructuring and adaptation in physical, social and emotional aspects of an individual's life. Two important features of recovery were highlighted. First, whilst aspects of pre-stroke life may be used to describe individual progress, no end-point to recovery was identified as informants described and anticipated life with stroke. Second, informants focused on the social context of recovery where engagement in the social world was emphasized over discrete physical function. Although no common path of recovery was found, it is recommended that stroke services are structured to take account of the long-term needs of stroke patients and their families in their home environment.

Keywords: interviews, lived experience, meaning, patient experience, phenomenology, stroke recovery, health services research

INTRODUCTION

Observation by the author of nursing practice in a stroke rehabilitation unit in the north-west of England, and discussions with nursing staff, highlighted difficulties in providing a sensitive rehabilitation service. Staff recognized they had only limited opportunity to design rehabilitation interventions that were able to equip people who had experienced stroke to negotiate new and meaningful lives. They anticipated that the structure and

content of nursing interventions was essentially artificial when compared to the realities of continuing rehabilitation at home. The need for a greater understanding of the meaning of living with stroke was identified.

The predominant approach that underpins health care provision for people with stroke is rehabilitation, which aims to help individuals with a disability return to optimal effectiveness in daily living (Catanzaro 1993). The limitations of traditional models of rehabilitation, which are underpinned by medical principles of cure, have been articulated consistently (Beardshaw 1988, Eubanks 1990, Pott 1992, Braden 1993, Pawlson 1994) and a clear agenda for developing nursing interventions which focus on the social dimensions of recovery is

Correspondence: Christopher Burton, Department of Primary and Community Nursing, University of Central Lancashire, Greenbank Building, Preston PR1 2HE, England. E-mail: c.burton@uclan.ac.uk

evident (Morse & Johnson 1991, Stroke Association 1994, Nolan *et al.* 1997). Such development must, however, take account of how patients themselves experience recovery from stroke, rather than professional interpretations of holism alone.

LITERATURE REVIEW

Stroke recovery receives only limited description in the nursing literature. As a disease process the biomedical interpretation of stroke (neuronal and functional recovery) or a two-stage model (acute and rehabilitation phases) appear to predominate (Speech & Dombrov 1995). There is a developing body of stroke rehabilitation literature that recognizes the importance of including the patient's perspective in outcome measurement, by the development of sensitive outcome assessment strategies (Seale & Davies 1987, de Haan *et al.* 1993, Wyller *et al.* 1997).

It is clear that, whilst studies on the experience and acceptability of care and therapy can be found (Pound *et al.* 1995, MacDuff 1998), there is generally a dearth of literature that focuses specifically on the individual's experience of the disease itself (Doolittle 1991, McLean *et al.* 1991). The most recent review of literature in this area was published in 1997 (Hafsteinsdóttir & Grypdonck 1997), and combines the findings of four studies (Mumma 1986, Doolittle 1991, Folden 1994, Häggström *et al.* 1994) and one earlier review (Doolittle 1988). Although no account is given of the strategies used to identify suitable papers to be included in the review, the limited number is likely to be representative given the plethora of calls for more research in this area.

Whilst the study undertaken by Mumma (1986) highlights patient perceptions of loss, a later, and more extensive, ethnographic study demonstrates a recovery path for stroke (Doolittle 1992). This study was set in the context of in-patient care and discharge, and brings to life the extent of the challenges and dilemmas that people who suffer a stroke experience. Seven themes were identified in the data: stroke in evolution, meaning of hospitalization, living with uncertainty, differing medical and personal views, facing the night and discharge home. Although these themes focus attention on the experience and psychological consequences of physical disability, the findings suggest the importance of the social context in the way in which participants evaluated their own recovery.

Doolittle's (1992) study strongly suggests that patient and professional interpretations of recovery can differ significantly, and consequently the reference frames for the evaluation of recovery can be at odds with each other. Professionals appear to evaluate progress using benchmarks relating to functioning, predominantly from a physical perspective, whilst stroke sufferers themselves frame their progress using activities that bring meaning to their life before stroke. A study by Folden (1994) builds on the understanding of stroke from the lived experience, and suggests that stroke patients may be able to accept that a return to their pre-stroke life is impossible. They are able to set personal goals to help them undertake some of their pre-stroke activities. This definition of recovery differs significantly from that suggested by Doolittle (1992), where a return to pre-stroke life was the predominant personal recovery target.

The study undertaken by Häggström *et al.* (1994) attempted to elicit both the experience and future expectations of people living with stroke. The methodology included the use of photographs depicting either an individual eating independently or being helped to eat by a nurse to facilitate narration. The 10 study informants had been living with stroke for at least 18 months, were receiving some form of continuing care in an in-patient setting and had been involved in a study of post-stroke eating problems. Four themes were identified: uncertainty; sadness and mourning; gratefulness, hope and satisfaction; and isolation. Importantly the study demonstrated the importance of ensuring the integrity of an individual's life history after stroke, as extensive reinterpretation may be required for successful adaptation to sequelae.

The follow-up time-frames for studies included in this study and the review by Hafsteinsdóttir & Grypdonck (1997) are detailed in Table 1. Participants included in the studies of Folden (1994) and Doolittle (1992) were tracked for no more than 6 months, and may not therefore reflect important aspects of long-term recovery. Doolittle's (1992) study concentrates primarily on the point of discharge from an institutional setting to the patient's home. Whilst the studies undertaken by Mumma (1986) and Häggström *et al.* (1994) did include people who had been living with their stroke for over 6 months, both studies were cross-sectional in design. This may reduce their ability to describe the 'process' of stroke recovery from the perspective of an individual patient.

Study	Sample	Design	Follow-up
Mumma (1986)	60	Cross-sectional	Informants were at least 3 months post-stroke
Doolittle (1992)	13	Longitudinal	Up to 6 months post-stroke
Folden (1994)	20	Longitudinal	Up to 1 month post-stroke
Häggström <i>et al.</i> (1994)	29	Cross-sectional	Informants were at least 12 months post-stroke

Table 1 Studies describing the experience of stroke identified by Hafsteinsdóttir & Grypdonck (1997)

One further study identified for this review utilized a phenomenological approach to elicit the experiences of stroke during the course of the disease (Nilsson *et al.* 1997). Ten informants who had suffered a stroke within the preceding 3 months were included. Each informant was interviewed twice. The data were contextualized by the deductive application of a theory of developmental crises (Erikson 1982). Whilst there are similar reservations about the ability of the research design to capture the process of stroke recovery, the overwhelming totality of stroke, and the struggle to grasp the implications of stroke are evident.

In recent years there has been an increasing emphasis on the inclusion of the user perspective in the design, delivery and evaluation of public services (Pollitt 1988). Such inclusion must be underpinned by a comprehensive understanding of the experience of illness to ensure the appropriateness and effectiveness of services. This review demonstrates that there is a need for research that explores the experience of living with the effects of stroke from a long-term perspective.

THE STUDY

The aim of this study was to identify the lived experience of recovery from stroke from the patient's perspective. Specifically the issues and themes identified by patients to describe their own recovery over time were sought.

Methodology

The philosophical framework adopted in the study was phenomenology, as an understanding of the 'meaning' of life with stroke was sought. It assumed that the underlying essence of this meaning would emerge through the reflective description of an informant's own world (Roche 1973, Ricoeur 1976, Strauss & Corbin 1990). Verbal expression of this description could be fixed in text, where the meaning intended by the speaker can be located (Ricoeur 1971, Klemm 1983). The principles of grounded theory methodology were used to elicit and clarify meaning from interview transcripts. The strength of grounded theory relates to the process of the constant comparing of emerging concepts within the data to guide further data generation and

comparison (Glaser & Strauss 1967). Emergent concepts are thus grounded or embedded in the data.

Study population

The research aim required that a tracking approach was adopted where informants were followed over a significantly longer time than previous studies undertaken in this area. A decision was taken therefore to limit the number of informants with a view to undertaking more in-depth and long-term study. A total of eight people, two of whom refused consent, were approached for inclusion in the study. All those approached had been admitted to the rehabilitation unit of a district general hospital in the north-west of England with a diagnosis of first stroke. Some of the biographical characteristics of the informants are summarized in Table 2.

Ethical considerations

Ethical approval was obtained from the local research ethics committee. Consent was obtained prior to inclusion, and for audio-taping of interviews. Ethical approval required that informants were free from dysphasia, had no history of clinical depression preceding their stroke, had no evidence of cognitive impairment, and had no significant medical history at the time of their stroke likely to influence their recovery.

Interviews

All informants were interviewed individually in hospital following their initial admission following a stroke. Initial interviews were informal and unstructured to enable maximum free expression (Morse & Field 1995), with informants being asked to tell the story of their stroke. Further data were collected at monthly intervals for at least 1 year. Follow-up interviews were used to explore issues raised at earlier interviews, and to explore new issues as they arose. The total number of interviews undertaken for this study was 73, ranging from eight with informant C to 15 with informant E.

The mean length of interviews was 35 minutes; however, individual interviews varied significantly. This variation was mainly in response to contextual features, including emotional reactions and the wishes of informants. A log journal was maintained throughout the

Table 2 Study Informant profile

Informant	Sex	Age	Marital status	Discharge destination	Employed at time of stroke
A	Male	78	Married	Home	Yes
B	Female	64	Widowed	Home	Yes
C	Male	81	Widowed	Nursing home then home	No
D	Female	68	Single	Home	No
E	Female	61	Divorced	Home	No
F	Female	52	Married	Home	No

duration of the study, in which reflections on the process of data generation and analysis were recorded in order to ensure that the contextual features of the study were accessible for analysis.

All informants were aware of the use of a tape-recorder, and were offered copies of the audio-cassette on completion of the study. All interviews were conducted in private, and informants were reassured about confidentiality in the reporting of the study findings. All interviews were transcribed verbatim as soon as possible after each interview. Audio-cassettes were kept to enable further clarification of the transcript if required.

Data analysis

The data were analysed continuously throughout the duration of the study (Strauss & Corbin 1990). This included documenting key reflections alongside interview transcriptions, so that data could be revisited in later interviews and contextual features explored (Glaser & Strauss 1967). All transcripts were read in entirety to aid 'immersion' in the data and to generate a naive interpretation from an initial sense of informants' stories. The purpose of this interpretation was to guide further analysis of data by identifying initial codes. Content analysis was used to organize the data so that codes could be condensed where possible into a matrix of themes and sub-themes. The content of the log journal was reviewed alongside each stage of the data analysis to ensure that the original context of the data was maintained.

Trustworthiness

Koch (1994) maintains that to establish the trustworthiness of a study such as this, three issues are important: credibility, transferability and dependability. The credibility and dependability of the study may be witnessed to some degree in the justification for the decisions made in the design of the study, and in the maintenance of a log journal. This was used to explore experiences, dilemmas and personal learning throughout the duration of the study. The content of the journal was subject to peer review and debate with a nurse academic experienced in qualitative research methods.

FINDINGS AND DISCUSSION

Recovery from stroke involved restructuring and adaptation in all aspects of an individual's life. Abilities to pursue tasks and activities that had previously been taken for granted presented new challenges, requiring appraisal, considerable effort and learning, and re-appraisal. Social roles were challenged and subject to enforced revision, with once comforting and welcoming environments appearing as potentially hostile territory.

The emotional responses to stroke were often extreme in nature, with highs and lows that often appeared to show to the external observer little correlation to the actual situations in which the informants perceived themselves. Individual reference frames for recovery were complex and highly specific to each informant. Whereas progress to specific goals or activities could be highlighted by informants, this was set in the context of pre-stroke life activity. It appeared difficult for informants to view modest clinical improvements that had been detailed by health care professionals in a positive light.

Research in this area has tended to focus on physical, emotional and social recovery (Hafsteinsdóttir & Gryphonck 1997). Whilst these three recovery themes were evident in the data, the lack of integration of themes appeared to be important. The path of recovery from stroke reported by informants was extremely varied in the types and severity of physical, emotional and social problems encountered, and the personal implications of these problems. The process of restructuring of life after a stroke appeared to incorporate a number of physical, social and emotional issues that varied as an individual adapted to their individual circumstances and contemplated the implications of their stroke on their future lives.

For the purposes of this paper each theme and its corresponding sub-themes are described independently.

Issues in physical recovery

The physical effects of stroke can be extremely varied, and have been shown to depend principally on the site of the precipitating cerebral incident (Speech & Dombovy 1995). The classical physical symptom is a unilateral weakness; other symptoms can include sensory and visuoperceptual disturbances, incontinence, dysphasia and dysphagia. Physical recovery has been described in a number of ways, from either a biomedical or rehabilitative viewpoint (Speech & Dombovy 1995). Biomedical models of recovery focus on the viability and process of neuronal recovery, whereas rehabilitative models describe physical recovery in terms of performance in activities of living, usually predetermined by health-care professionals.

Initial personal experiences of stroke

Informants generally viewed their stroke as an intensely personal experience, although there appeared to be a tendency to view the physical effects as being detached from their body as a whole. Few references to an affected side or limb were prefixed with an adjective:

At the time, it all seemed to come over me all of a sudden. Now it's really just this one here [pointing to leg].

The profile of physical recovery was, although complex, similar between study informants. The initial stroke was

experienced in a number of ways, depending on the type of stroke, but feelings of suddenness and overwhelming catastrophe were evident.

Two informants reported sensing their stroke in progress, as if their bodies were disappearing from beneath them, whereas for others the fear of not knowing what was going on proved overwhelming. The nature of stroke onset has been described before, where stroke sufferers have identified a complete loss of control, or complete disability, although clinically the stroke involved only part of the body (Doolittle 1991). Healthcare professionals have tended to regard a stroke as neuronal in nature, and tend therefore to refer to a one-sided paresis or weakness.

All those in the study sample were admitted to hospital as a result of their stroke and received rehabilitative care and therapy. In the United Kingdom (UK) stroke patients are increasingly likely to be admitted to hospital. The most recent estimate of the hospital admission rate for stroke patients is 85% (Stroke Association 1999). After admission, three informants continued to perceive a worsening of their condition, despite being fully awake and alert. One informant described this as feeling that:

Everything continued to get worse. It was as if bits kept closing down. I felt that this couldn't really be happening... not in hospital.

This provoked feelings of fear, especially not knowing when and where the process of experiencing the stroke was going to stop. There was a strong sense of disappointment that this was happening even though they were in a hospital environment and were receiving care and treatment.

Early recovery

The first steps towards recovery were usually experienced in terms of increasing sensation, or progress towards goals. Goals in this instance were usually set by professionals. The inability to plan ahead in the early stages of stroke was highlighted by one informant:

I didn't really know what I was supposed to be doing. All I could think about was what I used to be able to do. I didn't know where to start.

There were significant differences in the way that individuals experienced initial recovery, for example improvements in speech, sensation and movement, dictated usually by the physical effects of their stroke.

Slowing down

At different times throughout their recovery, all informants experienced periods when they felt that their recovery was halted. For most this was perceived in one of two ways — either that their existing level of function was the best that it could be, or that their condition as a whole was worsening. What was clear, however, was the

lack of preparation that informants had for these instances, and the negative feelings this precipitated. The slowing down of recovery was often associated with feelings of despondency and frustration, and evoked reflections on pre-stroke life:

I wanted to get to the chair by the window. I just couldn't get to see the garden. It was always in the same place that I stopped. I just could never seem to get any further. I thought I had been doing well.

A common feature of the path of recovery from stroke described by Doolittle (1991) is periods of stability in physical functioning, described as 'plateau periods'.

New challenges

The long-term nature of stroke and recovery from stroke was strikingly evident within the data:

You can't get away from it. If you've had a stroke, then you've had a stroke. Its always with you.

All new problems and situations which the individuals in the sample experienced were mediated by the fact that they had suffered a stroke. The ability to deal effectively with these situations was often affected by the features of physical recovery. When new coping mechanisms had been established and were perceived to be successful, informants felt more able to do things even though the clinical level of function remained constant:

The hand doesn't do any more than it did. I'm just coping better with it. I'm able to do a lot more now.

This would suggest that actual adaptation in discrete physical activities was not of prime importance, rather it was the ability to cope with physical limitations that was valued by informants.

Issues in emotional recovery

Although individuals varied greatly, a number of consistent themes were identified in the data that described features of emotional recovery from stroke. The impact of the stroke precipitated a range of emotional responses, with no apparent linear sequencing of responses over time. Rather than a series of emotional hurdles which patients had to overcome, emotional recovery was reactive, undirectional and unpredictable.

Uncertainty

The initial overwhelming nature of stroke onset precipitated feelings of immense uncertainty in study informants. Individuals felt unprepared for their stroke: they feared what was happening to them, and that they were going to die. For those who perceived a worsening of their stroke in hospital, these feelings appeared to be most strongly

marked. The development of the stroke left them feeling uncertain about the future.

Each new transition of care, and especially discharge home, left informants feeling unable to plan and unsure about the future. Uncertainty was often perceived as extending into the future, when responses to problems or crises could not be visualized or anticipated:

Well I always thought I would be able to cope. With the stroke I don't know what I would do if [the family] moved away.

An evaluation of a community stroke service, undertaken from a medical anthropological perspective, supports the recognition of uncertainty as an important area on which nurses might focus their efforts (Hart 1998).

Hope

Hope appeared to be a major feature of emotional recovery in the first few weeks after stroke, with two informants identifying early physical recovery with the possibility of full recovery at a later stage:

By the time I got to the rehab unit I seemed to be doing OK. I thought that this wasn't going to be as bad as I first thought it would be. I suppose that gave me a push in there to do well.

Nilsson *et al.* (1997) identified that hope may be an important feature of early post-stroke recovery due to the potential for rapid and spontaneous recovery during the first few weeks after stroke. Any early recovery can help to reinforce the possibility of full recovery in time. Progress towards goals set by professionals appeared to be important in helping informants to be hopeful about recovery, although this was challenged by the reduction of professional rehabilitation input after discharge home where informants no longer had daily access to therapy services.

Loss of control

All informants reported a perceived loss of control over their bodies and their individual circumstances. These feelings were again anticipated for aspects of their future lives. Although physical loss could be attributed to a specific and discrete functional activity, this tended to be translated by informants to a total loss in a major area of an individual's life:

I can't grip properly with this hand. It means that I can't do anything. I mean if I go the [the pub]. What would be the point?

This translation may reflect the overwhelming nature of stroke. It is interesting to note that as recovery progressed, some informants appeared to focus on positive aspects of their life which they felt they had control over:

[Friend] comes with me. We've worked out this way for me to have a game of [cards]. I think they can see them and cheat. I suppose it's worth it though. Better than not going at all.

In the early days of their stroke, particularly in those who experienced a stroke in evolution, the loss of control appeared to relate both to uncertainty about the immediate situation and the future. During later recovery, however, the focus of control appeared to relate to feelings of being dependent on others. Feelings of needing help and direction to perform mundane tasks, such as dressing and sitting, provoked negative reactions in all informants.

Anger/frustration

The loss of control associated with the aftermath of stroke, both in physical and social activities of life, provoked a strong sense of frustration in study informants. This linkage between control and frustration appeared to be most strongly related to the physical effects of stroke. Often, frustration was directed towards the parts of the body affected by the stroke:

At first nothing seemed to work. Now it's just this [holds up hand]. I could cope a lot better if it would just do a little bit more. It drives me up the wall.

A number of informants reinforced this frustration by making comparisons with their pre-stroke life. One patient appeared to be particularly bitter about his stroke, and the impact it had on all aspects of his life. All informants recounted a sense of being unable to prepare for their stroke, and that the suddenness and unexpected nature of their illness had prevented them from coping better.

Issues in social recovery

It was clear from the data that each informant's stroke had profound implications that pervaded all aspects of their social world. Two of the informants had been forced to give up part-time employment. Balances in family and social networks were disrupted, and informants expressed concern and difficulties in re-defining their perceived contribution to social and family life. Each stroke had precipitated immense changes, the repercussions of which appeared to be never-ending.

Changing roles

Some informants felt resigned to accepting a passive role in interaction with hospital staff, particularly in the early stages of their stroke. This appeared to be mediated by perceptions of the importance of knowledge held by the professionals who were working for them. Informants who had continued to work after retirement expressed particular difficulties in coping with this situation:

I felt stupid. You know. Being taught to chew my food. I mean I know why. [speech therapist] told me why we were doing this, but it didn't really help.

All informants reported that their roles and responsibilities were threatened, notably in areas of work, finance, family and social networks. Although perceptions varied between each individual, a pattern was recognized in the data involving the continuous appraisal and re-appraisal of social role:

I had always driven us to [supermarket] on Friday evenings. I couldn't do it anymore. I suppose it's daft but it was what we did together. Not any more. I help put the things away. Well as much as I can. But it's not the same.

Re-appraisal did not necessarily imply an acceptance of the new situation, rather than an adjustment of role. Often these adjustments were evaluated in terms of pre-stroke life, and only rarely in terms of a positive step on the road to recovery.

Isolation

All informants at some time in the study referred to feeling as though they were isolated or stuck in a cage: the cages ranged from their bodies, to the hospital and their homes. All references to this were accompanied by feelings of frustration and anger. Waiting appeared to be a key feature of this isolation; waiting for help, waiting for family and friends to come:

I always feel that I'm just stuck in this chair, waiting for something to happen. It's really difficult.

Reflections on previous life

Informants often felt that their new lives were essentially unfamiliar. Some activities previously enjoyed no longer appeared to give them pleasure. No informants referred to their present life on a par with their pre-stroke life. Even when specific activities had been re-mastered, the social meaning of those activities appeared to be missing:

I could manage to hold [pack of cards]. I suppose I enjoyed doing it again. But when I think back to [card parties] it wasn't the same.

All informants reported that they would not be able to forget their stroke, and that it would be an important issue for the rest of their lives. They felt that the stroke would have an impact on all aspects of their future lives. It appeared that the 'real' work of recovery began when informants felt that they were on their own, and professional input had been stopped. Some reported that professional input was artificial, where the context of therapeutic activity that was designed to help them undertake specific activities bore little resemblance to their own home environments:

They teach me how to do bits again. But then I go out and look at [the local environment] and it's all so unreal.

The clinical environment differed substantially from the reality of informants' own social environments. Inform-

ants seemed to have little support in facilitating the adaptation of skills learned with staff in the hospital.

Study limitations

The hospital where study informants were recruited was typical of many UK district general hospitals, with a profile of stroke services consistent with the predominant national pattern (Stroke Association 1999). The small number of informants who contributed to the study allowed a longer follow-up relative to other research in this area. Whilst this limits the generalizability of the study findings, it does allow the exploration of the transferability of themes and concepts to the full range of settings and services that aim to provide rehabilitation for people with stroke.

CONCLUSION AND RECOMMENDATIONS

Understanding how patients experience illness is an essential prerequisite to the development of appropriate strategies to facilitate recovery. Most studies have tended to describe stroke recovery using an incremental linear model. Doolittle (1992), for example, details recovery as phases which relate to the time frame of her study. As a result, her interpretation of recovery from stroke can be seen to infer a two-stage model comprising of acute and rehabilitation phases. The limitation of this approach is that it supposes a normal path of recovery, with phases of stroke that have a core content. Application of this description of recovery to the development of nursing rehabilitation interventions necessarily focuses attention on the physical domains of recovery within a time-frame largely dictated by the boundaries of professional service.

The study described here details the experiences of recovery from stroke into the long-term by tracking patients for at least 12 months. Whilst the descriptions of some experiences relating to the early stages of stroke reinforce those of other researchers, the nature of individual definitions of recovery may require a re-appraisal of existing models of stroke service provision. This study suggests that stroke is an intensely personal experience, involving the rebuilding and restructuring of an individual's world. The real work of rehabilitation described by informants was the translation of learning from the institutional setting to their home environment. The social context of recovery was extremely important where the focus of recovery was enabling participation in the social world through adaptation and the development of coping skills, rather than improvement in discrete physical function alone.

The complex nature of recovery and the range of possible stroke sequelae identified in this study highlight the considerable challenge that stroke sufferers and their carers can face. Rehabilitation programmes must equip

stroke sufferers and their carers with the support, skills and knowledge to shape their future lives in a meaningful and fulfilling way. A recent survey undertaken by a stroke patient advocacy group suggests that there is much to be done in improving the appropriateness and utility of existing service provision (Stroke Association 1994).

Implications for practice

Existing frameworks to consider the development and delivery of stroke services tend to be underpinned by professional interpretations of recovery, and may have limited relevance to the concerns and experiences of the individual. Rather than focusing on acute and rehabilitation services, new strategies that reduce existing boundaries of service provision and help patients and their families adapt to life with stroke need to be explored.

It would appear that any new strategy should include at least three features. The co-ordination of service provision requires an over-arching perspective from stroke onset into the long-term. To be relevant this perspective must be underpinned by an appreciation of patients' experiences of stroke. The expansion of nursing interventions aimed at the development of coping and adaptation skills at home after discharge from in-patient services requires consideration. Lastly, the importance of the social context of recovery after stroke should be recognized. This would require the imaginative integration of hospital and community rehabilitation services, for example through hospital out-reach or community in-reach, to enable them to be able to respond flexibly to patient and carer need.

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Re-thinking stroke rehabilitation: the Corbin and Strauss chronic illness trajectory framework

Christopher R. Burton PGCert HE BN RCN
University of Central Lancashire, Preston, England

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The dramatic effects of a stroke can have far-reaching implications for patients and carers. Effective recovery involves a considerable array of coping strategies that facilitate and promote engagement in the social world. Their development is a long-term process that requires considerable effort, motivation and enterprise on the part of patients and their families. Traditional approaches to the provision of stroke rehabilitation services, however, appear to be underpinned by frameworks that are short-term in outlook. As a consequence, nursing interventions often focus on the progression of the patient through the care system, rather than on facilitating future recovery. Much of the work of stroke recovery is consequently done by patients and their families at home, with little provision of ongoing professional help and advice. This paper explores the application of the Corbin and Strauss Chronic Illness Trajectory Framework for stroke. In particular, the major concepts of the framework are applied to a vignette derived from a longitudinal study of patients' experiences of recovery. The trajectory framework is shown to be a useful structure that has the potential to enhance the appropriateness of nursing interventions for stroke patients. However, the validity of the framework can only be established through its application and evaluation in clinical practice. The purpose of this paper is to contribute to a debate that encourages consideration of the framework's utility for nurses to enhance the stroke rehabilitation experience.

Keywords: Corbin and Strauss Chronic Illness Trajectory Framework, nursing, stroke, stroke rehabilitation, vignette

INTRODUCTION

The demand placed on United Kingdom (UK) health care resources by stroke has precipitated its priority status in national health prevention, treatment and management strategies (Department of Health 1992, 1997). The Stroke

Association (1994) maintains that 350 000 people in the UK are directly affected by stroke, and that each year 100 000 people will suffer a first stroke. Seventy per cent of stroke patients survive the initial disease onset, and will require some form of rehabilitation. Stroke can have a catastrophic impact on an individual, with a wide range of far-reaching physical, psychological and social sequelae. It is perhaps unsurprising that providing care and rehabilitation to these patients and their families represents a considerable proportion of nursing workload.

Correspondence: Christopher Burton, Department of Primary and Community Nursing, University of Central Lancashire, Greenbank Building, Preston PR1 2HE, England.
E-mail: c.burton@uclan.ac.uk

After the initial disease onset, nursing interventions for this client group are generally geared to the restoration of independence and the development of coping skills and strategies (Nolan *et al.* 1997). Rehabilitation, however, requires the input of a range of health care professional groups including medicine, nursing, physiotherapy, occupational therapy, speech therapy and clinical psychology. Where effective collaboration is achieved, for example in the development of a stroke unit, there are clear benefits to stroke patients, including reductions in associated mortality and morbidity (Stroke Unit Trialists Collaboration 1997).

From a UK perspective, however, the services stroke patients receive are at best patchy (Stroke Association 1999). A clear agenda for the development of stroke rehabilitation services has been proposed by the Stroke Association (1994) which re-focuses attention on the quality of life of stroke patients and their families, and long-term care maintenance. Nurses are beginning to tackle this agenda by, for example, developing new roles. These include the role of stroke co-ordinator, responsible for the integration of multidisciplinary input, or the stroke specialist nurse who uses in-depth knowledge and expert skills in contributing to the management of patient care (Stroke Association 1999). A clear picture persists in the literature, however, of the failure of stroke services to achieve a seamless service that equips patients and carers to cope with the long-term effects of stroke (McLean *et al.* 1991, Stroke Association 1999).

Nurses undoubtedly have a key role to play in the provision of rehabilitation to stroke patients, although this role is poorly defined (Nolan *et al.* 1997). In particular, little is known of what constitutes effective nursing practice in terms of improving the outcomes of stroke rehabilitation. Nurses appear to adopt various roles in the provision of stroke services including care giving, rehabilitation maintenance and management, which are geared to the enhancement of the experience and effectiveness of rehabilitation (Waters 1987, O'Connor 1993, Waters & Luker 1996).

THE NATURE OF REHABILITATION: A REVIEW OF SELECTED LITERATURE

Generally, the literature presents a complex picture of the nature and purpose of rehabilitation, with an array of often conflicting models and frameworks (Nolan *et al.* 1997). There is, however, a clear agenda emerging which emphasizes the importance of social and psychological aspects of rehabilitation, in addition to promoting physical recovery. For example, Waters (1996 p. 242) describes rehabilitation nursing as 'the whole process of enabling and facilitating the restoration of a disabled person to regain optimal functioning (physically, socially and psychologically) to the level that they are able or motivated to achieve'. Although this description would emphasize the nursing

role in stroke rehabilitation as an holistic enterprise, the realities of the clinical environment can mean that this definition is at best optimistic. Nurses are part of a team, and collaborate in their work with a number of professional groups who may hold different beliefs about the meaning of rehabilitation.

The predominant framework that currently underpins a significant proportion of rehabilitation services is the International Classification of Impairment, Disability and Handicap (ICIDH) (World Health Organization, WHO 1980). This framework is composed of four key concepts: disease, impairment, disability and handicap. These concepts appear as a linear causative structure, where stroke, as a disease, can cause specific physical and neurological symptoms. These symptoms in turn result in functional deficits, or disabilities, which subsequently handicap an individual's ability to maintain their wider social role and function. The purpose of rehabilitation then is to return the person to their social world by reducing symptoms and disabilities.

Although it has been proposed that the ICIDH framework concepts are interdependent rather than causative in nature, the application of the framework to diagnosis, treatment, the measurement of health, and the evaluation of the outcomes of alternative rehabilitation interventions, has been advocated (Halbertsma 1995). This would, however, imply the legitimate consideration of each of these concepts as outcomes of rehabilitation in their own right. In adopting such a reductionist approach, the ability of the framework to address the complexity and diversity of the experience of a disabling illness such as stroke may be lost.

Whilst application of the existing ICIDH framework to stroke focuses attention on the wider consequences of illness, it has two further limitations. First, the framework does not emphasize the wide range of behavioural and environmental factors that are important in shaping the incidence of, and recovery from, stroke. For example, socio-economic status, age, education and/or training, and personality/psychological make-up, have been shown to affect recovery (Speech & Dombovy 1995). Second, consideration of the framework concepts as causative in nature can encourage a diagnose-and-treat approach to rehabilitation (Dickson 1996), where the aim is to facilitate recovery that allows the patient to progress through care settings and to home. A new ICIDH framework (ICIDH-2) has been proposed and is currently being trialled (WHO 1999), and will hopefully begin to influence the planning of stroke services in the near future. It is proposed that the revised ICIDH-2 will reduce these limitations by highlighting the often negative impact of societal and environmental factors that affect an individual's participation in the social world.

Waters' earlier holistic definition of rehabilitation encourages a broad perspective on recovery from stroke

that includes more than physical restoration alone (Waters 1990). It does, however, propose an ultimate goal for rehabilitation, where at some point the patient will have recovered, depending on patient ability and motivation, and the successful resolution of problems before discharge. Research into patients' experiences of stroke indicates, however, that the process of recovery is gradual and non-linear and tends not to be defined by patients in terms of physical activity alone (Hafsteinsdóttir & Grypdonck 1997). Of crucial importance to patients is their level of involvement in the wider social world (Doolittle 1992, Folden 1994, Nilsson *et al.* 1997), including their family roles and responsibilities, social activities, lifestyle and employment. Regaining this involvement after stroke often requires considerable work and effort, incorporating experimentation or trial and error, and begins at a time when professional involvement in their recovery is being reduced (Doolittle 1992). Further, the environments in which rehabilitation is provided for patients are often artificial and bear little resemblance to their own circumstances. For example, negotiating obstacles at home and in the surrounding neighbourhood is often very different to clinical environments which are designed with the physical limitations of stroke patients in mind.

The challenges for patients and nurses associated with facilitating successful involvement in the social world after stroke are unlikely to be met by short-term, curative approaches to rehabilitation. As Northway (1997) maintains, nurses must recognize, and act on, those factors that hinder an individual's adjustment to disability, but within the context of wider social, economic and environmental factors that promote oppression. The degree to which this is possible, however, will relate to the underpinning philosophies of stroke service provision. This paper proposes that the Corbin and Strauss Chronic Illness Trajectory Framework (hereafter referred to as the trajectory framework) has the potential to shape a new approach to rehabilitation that may enhance the experiences of stroke patients and their families (Corbin & Strauss 1992).

THE TRAJECTORY FRAMEWORK

The trajectory framework, which purports to describe the experience of chronic illness, has evolved during 30 years of research and observation of practice. The framework as a grounded theory, was developed from an extensive research programme on dying, and was refined in studies that included a range of settings and patient groups (Corbin & Strauss 1992). Since its development the trajectory framework has been applied to a number of patient groups: cardiac illness (Hawthorne 1991), cancer (Dorsett 1992), multiple sclerosis (Miller 1993), diabetes (Walker 1992), and elderly patients with chronic illness (Robinson *et al.* 1993). However, its application to stroke rehabilitation has received little attention.

The central concept of the framework is a trajectory, or illness course. For individual patients this course represents the cumulative effects of a disabling illness including physical symptoms, and the impact of the illness on an individual's social world challenging perceptions of self-identity, termed biography. Although individual trajectories can only be mapped retrospectively in light of responses to illness, a prospective view of a trajectory can be based on the knowledge, beliefs, values and experiences of patients and professionals (Thorne & Robinson 1988). The key to the utility of the framework lies in the assumption that although each individual with a chronic illness experiences the disease process in a unique way, there are common phases which involve changes in health status and intervention need.

The first stage in a trajectory (pre-trajectory) occurs before the onset of symptoms, and consequently before a formal diagnosis is made. This emphasizes the importance of illness prevention within a framework for managing chronic health problems. When signs and symptoms appear (trajectory onset), these can pose a significant threat to the physical, social or psychological integrity of an individual (crisis phase). The onset of symptoms may precipitate a period of illness that requires active intervention, usually in an in-patient setting, to prevent the worsening of symptoms, or the prevention of complications associated with the effects of the illness (acute phase). Where intervention is effective, a period of stability may be reached which will require varying degrees of intervention to maintain individual health (stable phase). An individual will, however, experience challenges to their recovery either directly or indirectly associated with their illness which require a reappraisal and adaptation of interventions, usually without admission to a hospital setting, to promote coping and stability (unstable phase). Responses to these challenges to recovery will at some point, however, be unsuccessful, and the patient's recovery may deteriorate (downward phase) to such a point that the patient may be terminally ill (dying phase).

The phases of an illness trajectory do not represent a rigid framework for the linear consideration of a patient's response to illness. Each phase, for example, may include several sub-phases which include movement in either direction along a trajectory which can be of considerable duration. This dynamism reflects the continual nature of adaptation that characterizes living with chronic illness (Locker 1983, Chilman *et al.* 1988).

The purpose of stroke rehabilitation nursing within this framework would broadly appear to be to manage a patient's illness trajectory with reference to the biographical effects of stroke. In practice this requires both the acquisition and use of in-depth knowledge relating to an individual's biography through active participation on the part of the patient and family, and importantly, the provision of rehabilitative interventions geared to the

restoration of independence. In this way professional intervention can be appropriate to the individual. According to Corbin and Strauss this may include facilitating the adjustment of biographical and social dimensions of illness to encourage coping and adaptation (Corbin & Strauss 1992).

METHOD

This paper seeks to evaluate the application of the trajectory framework for stroke, and is based on the retrospective analysis of data generated in a previous study undertaken by the author (Burton 2000).

Corbin & Strauss (1992) recommend the evaluation of their theory based upon criteria proposed originally by Glaser & Strauss (1967). These are:

- the fit between the trajectory framework and the specific area of clinical interest;
- the ease of comprehension;
- its applicability to a variety of circumstances; and
- its utility to the individual practitioner.

Ultimately, however, a theory should have demonstrable utility in informing decision-making and nursing action, by empowering nurses to develop clinical practice (Sandelowski 1986).

Theory testing is a dynamic, cyclical activity and depends on continuous evaluation of theory over time (Molais 1991). A search of the literature using electronic databases demonstrates that the trajectory framework has yet to be applied to stroke. Consequently, these criteria provide a strategy for the evaluation of the trajectory framework in stroke through dialogue between research and practice. This paper will contribute to this dialogue by focusing on the fit between the trajectory framework and patient experiences of stroke, and will highlight its potential utility for nursing practice.

A range of methodological approaches to the evaluation of the trajectory framework can be found in the literature, including comparison with other disease frameworks (Dorsett 1992), analysis of nursing documentation (Robinson *et al.* 1997) and retrospective analysis of case studies (Rawnsley 1992). For this study, the framework will be applied to a vignette describing the experiences of one stroke patient tracked during a previous study of patients' experiences of stroke recovery. The study adopted a qualitative, tracking approach to data collection to enable in-depth exploration of the participants' experiences in depth (Morse & Field 1995).

This participant was initially interviewed in hospital and further data were collected at monthly intervals over a period of 14 months. Initial interviews were informal and unstructured to enable maximum free expression. Follow-up interviews were used to explore issues from earlier interviews further, and to explore new issues as they arose.

A total of 14 interviews were held, all but one with the participant and his wife. All interviews were transcribed verbatim. Initially, each transcript was read in entirety to aid 'immersion' in the data. Open codes were reviewed and condensed where possible into a coding frame of themes and sub-themes. A log-journal was kept throughout the study to ensure the original context of data was maintained. The vignette has been reviewed by the study participant.

Vignette

Robert was 78 years of age and married at the time of his stroke, and had been working part-time as a gardener for a young couple. Discussions about his life before stroke highlighted that he had been diagnosed with moderate hypertension by his general practitioner approximately 3 years before his stroke, and was taking antihypertensive medication. Although he was aware that he was at risk of stroke, the onset of physical symptoms was shocking for both Robert and his wife.

Robert had his stroke during the night when he was awake but in bed, and he remembered feeling a sudden onset of numbness, weakness and slurring of his speech. His wife recognized his symptoms, and telephoned the emergency services. He was admitted to an acute medical unit via the hospital accident and emergency department.

The early stages of Robert's admission to hospital were complicated by an extension to his stroke which again he was able to perceive. He described it as 'feeling his body fall away from him', and it precipitated tremendous feelings of fear and helplessness. Gradually Robert's condition stabilized with conservative and preventative treatment and he was transferred to the hospital's rehabilitation unit 8 days after his admission. When he arrived on the unit he was unable to weight-bear and had very limited ability in his arm and hand. His speech, although still slurred, had improved to a degree where he could participate in short conversation. He complained of feeling persistently tired.

His stay on the rehabilitation unit was of approximately 3 weeks duration, in which time he received physiotherapy for mobility and arm function, and occupational therapy to improve his ability to dress himself. By the time he was discharged, Robert could transfer between a chair and bed independently, and could mobilize with the help of one person and a walking frame. He was discharged home with follow-up physiotherapy arranged through visits to a day hospital. His wife was able to undertake some aspects of his physical care at home, particularly in helping him to wash and dress. Follow-up assessment by the community nursing services was arranged that aimed to ensure that his wife was coping with Robert at home.

I had interviewed Robert four times whilst he was in hospital, and during the last week of his stay he was enthusiastic about the prospect of returning home. His wife appeared optimistic about their ability to cope. When

he finally did get home, however, things did not go well. Robert became very loathe to use his walking frame and insisted on acquiring a wheelchair from a local voluntary organization. Although they lived in a flat, his willingness to move between rooms in the wheelchair decreased, and he spent more and more time in one room on a sofa. He was reluctant to go out with his wife, feeling that he was too much of a burden. He did, however, persuade a friend to take him to the local pub once a week in his wheelchair. He felt that this was his way of giving his wife a rest from coping with his stroke.

Although he maintained physiotherapy at the day hospital he was reluctant to practice activities at home. He expressed a fear of his home environment and feelings of anger that his home was no longer a comfortable and welcoming environment. Although over the next 2 months his hand function had not clinically improved, he attained an ability to manage a 'hand' of cards at the local pub using a 'shelf' constructed by a friend. This enhanced his outlook on his recovery and his motivation to tackle the effects of his stroke.

Although in most respects they were coping with the aftermath of his stroke, it was still an important feature of their life together. His wife, for example, had suffered a chest infection which required a short period of hospitalization. Robert's stroke required a re-appraisal of their usual coping strategies in that their daughter, who lived a considerable distance away, moved in for a short period to help Robert. In this way his stroke continued to shape his life, and his responses to new problems as they arose.

DISCUSSION

The vignette demonstrates a complex path of stroke recovery: the participant's route to home included three different care environments, emergency, acute and rehabilitation, each with a different intervention focus. Once home, some physiotherapy services continued to be provided in the hospital environment. The return home appeared to represent the most important transition of care and presented considerable challenges to Robert and his family; however, it was anticipated with enthusiasm. The impact of stroke on both the patient and family was clearly immense, requiring considerable learning, appraisal, adaptation, and the development of effective coping mechanisms. For example, although Robert received formal rehabilitation from a variety of therapists, particular difficulties were experienced in continuing this work at home.

Although there is a growing body of research which describes the physical, psychological and social aspects of stroke recovery, studies have tended to be either cross-sectional in nature or with only limited follow-up of participants over time studies (Mumma 1980, Doolittle 1991, Folden 1994, Häggström *et al.* 1994). The longitudinal nature of the study from which this vignette is

drawn provided the opportunity to capture the considerable work associated with effective recovery after professional input had been reduced. Doolittle (1992), for example, refers to a process of experimentation where stroke patients begin to learn to cope with stroke by trial and error. Much of this experimentation occurs at home, often without recourse to the knowledge and skills of health professionals, and may place considerable demands on the patient and family. This demonstrates the importance of maintaining a prospective vision when designing and implementing therapeutic nursing interventions that aim to promote long-term recovery, and is a central feature of the trajectory framework.

Descriptions of learning, adapting and coping at home by the participant were set within the context of abilities to participate in life activities that had a wider social meaning, for example playing cards. The repercussions of stroke for the social world of this participant and his family were extensive, and were a central feature of responses to a wide variety of issues. For example, the response to his wife's illness was mediated by a requirement to ensure that arrangements were made for his needs. The biographical component of the trajectory framework stresses the impact that illness can have on an individual's ability to participate in his/her social world, and the continual process of self-adaptation required to come to terms with an illness. Where stroke results in some form of disability, this component may, however, promote the adoption of individualistic models of rehabilitation. The emphasis is clearly on helping the patient to adjust their life-course to their disability. This has the potential to neglect the social and environmental causes of disability (Northway 1997).

With respect to the concept of trajectory phases, there are a number of similarities between the participant's recovery path and the framework. These are demonstrated in Table 1. Pre-trajectory issues related to risk-factors for stroke: the participant had hypertension for which medication had been prescribed. Considerable evidence from epidemiological studies highlights the risks of stroke associated with hypertension and smoking (Royal College of Physicians 1989). Corbin and Strauss highlight the importance of health promotion activities as a feature of implementing a trajectory model of nursing, where the focus of nursing care includes both the prevention of chronic illness and the facilitation of coping with the effects of disabling illness (Corbin & Strauss 1992).

The trajectory onset phase of stroke is characterized by the onset of symptoms which may be varied due to the differing types of stroke pathology. Responses to this phase may be mediated by a range of variables that can largely be attributed to the patient, for example where the symptoms were first experienced, the degree of severity of the disease, and the biographical components of the trajectory. In the case presented, the participant's wife

Trajectory phase	Vignette	Interpretation
Pre-trajectory	Recognition of risk factors	No signs or symptoms, but presence of stroke risk factors
Trajectory onset	Onset of signs and symptoms	Diagnostic period during which expert advice is sought
Crisis	Recognition of signs and symptoms Seeking expert/emergency intervention Stroke extension Feelings of fear and helplessness	Life threatening stroke requiring emergency/critical care
Acute	Confirmation of diagnosis	Hospitalization for the stabilization of stroke
	Conservative and preventative treatment Stabilization of condition	Prevention of post-stroke complications
Stable	Complex package of rehabilitation interventions Discharge home	Design and delivery of a multi-disciplinary stroke rehabilitation package Design and delivery of a continuing care package
	Development of coping mechanisms at home	
Unstable	Initial difficulties at home Wife's illness	Trajectory not maintained by existing care packages, but not requiring hospitalization
Downward Dying		

Table 1 Comparison of trajectory framework phases and vignette

was able to recognize the signs of stroke and act accordingly.

The crisis phase of the trajectory framework is defined by a life threatening situation requiring emergency in-patient care (Corbin & Strauss 1992). For this patient, emergency care was facilitated by admission to an accident and emergency facility. This aspect of stroke service provision may, however, be extremely variable. In the UK, initial stroke severity and the beliefs of health professionals about the appropriateness of hospitalization for stroke can mean that stroke patients are not always admitted to hospital (Anderson 1992, Stroke Association 1999). Indicating that further study of the trajectory onset and crisis phases of a stroke trajectory is required.

The acute phase is characterized by interventions planned and delivered in an acute care setting, either for active illness or for complications of active illness. In this vignette, the acute phase related principally to active illness and no further periods of in-patient care were experienced during the study time frame. At this time, the principal aims of treatment for stroke from the professional perspective are geared towards diagnosis of the type and severity of stroke, and stabilization of the patient's physical condition, including the maintenance of blood perfusion, hydration and nutrition (Gibbon 1995). Nursing interventions also focus on the prevention of complications including pressure damage and aspiration pneumonia.

Analysis of the vignette demonstrates that a stable phase had been reached by the time of transfer to the rehabilitation unit, and professional rehabilitation commenced. This stability would appear to relate to physiological status as a result of neuronal stability. Stability as defined by Corbin & Strauss (1992) implies that the trajectory of recovery remains on course as a result of a planned package of interventions.

The vignette demonstrates two challenges to the maintenance of the given trajectory: the participant's discharge home and his wife's illness. In both cases, the participant and his wife adapted to the trend of the trajectory without recourse to health professionals. The unstable phase is defined as when the course of illness is not controlled by planned services, but can be managed without recourse to an in-patient setting. The trajectory framework implies that the responsibility to manage a return to a stable phase rests with the professional (Corbin & Strauss 1992), and therefore has the potential to neglect the experimentation and adaptation by stroke patients and carers that often goes on unnoticed (Doolittle 1992).

Although the time frame of the original study was long in comparison to other studies in this area, it failed to capture events and responses which can fit the downward and dying phases of the trajectory framework. Further evaluation is required to clarify and refine the meanings of these trajectory phases for stroke patients. One of the most striking features of the vignette, however, is the persist-

onco of stroke as an important issue for future life, where responses to stressors and challenges are mediated by the effects of stroke. The trajectory framework consequently succeeds in presenting a matrix of concepts that emphasize the long-term nature of recovery from stroke.

The trajectory framework does not imply death to be the final stage of stroke recovery. Indeed, in some circumstances, health may be maintained or improved along the stable phase of the trajectory. What is implied, however, is that the experience of illness will be present until death, and that the individual response to subsequent health problems may be mediated by experiences along earlier trajectories. One of the most interesting points to emerge from this exploration is that patients, having entered the trajectory, do not actually emerge from it over time. The stroke survivor will continue to be a survivor of stroke. This has relevance to the reported psychological trauma of having been through and survived a life threatening situation, and may persist into subsequent acute and chronic illness patterns.

Implications for practice

At a strategic level, the development of a seamless stroke service requires collaboration across a range of professional groups and health and social care providers. The phases of the trajectory framework have the potential to provide an overarching perspective between in-patient and community care settings by focusing on the experiences of patients, rather than traditional boundaries of professional service provision. As the framework is grounded in the patient perspective of illness, it may provide a blueprint for the development of stroke services, without promoting the value-base of any one professional group.

The trajectory framework presents a realistic structure for clinical practice against which treatment and rehabilitation plans and goals for stroke recovery may be set and evaluated. It allows the consideration of a wide range of contextual issues, including patient biography, that affect the recovery path for stroke. This requires effective communication and collaboration with both patients and carers that is capable of eliciting in-depth information of pre-stroke life and patients' social worlds.

Corbin and Strauss (1992) define the process of trajectory management as:

- Identifying the patient's trajectory phase and setting goals.
- Assessing the factors likely to influence trajectory management (including resource and environmental constraints, and biographical factors).
- Determining which factors are to be targeted for manipulation.
- Implementing the appropriate nursing interventions and evaluating their effectiveness.

These activities require considerable knowledge of the full range of physical, social and environmental issues that affect stroke recovery, many of which may not easily be amenable to manipulation. Those that will be most amenable to manipulation will focus on the individual perspective, and may result in the reinforcement of individualistic models of disability criticized by Northway (1997). An appraisal of nurses' existing networks with statutory and voluntary organizations that have the capacity to influence social, physical and economic factors that affect stroke patient recovery would be required.

CONCLUSION

The trajectory framework is applicable as an alternative framework for the delivery of stroke rehabilitation services, and may be capable of resolving some of the deficiencies in traditional approaches to rehabilitation. The trajectory framework has the capacity to provide a long-term perspective on patient recovery that is capable of incorporating the full range of patient consequences from stroke. In addition it emphasizes the role of social and environmental constraints that have the capacity to affect recovery. Further clarification of trajectory phases and the role of patients and carers in trajectory management is, however, required. This may best be facilitated by the experimental introduction of the framework into clinical practice.

Adoption of the trajectory framework would require a considerable change in the focus of nursing interventions for stroke patients where they are based on a curative, short-term model of rehabilitation. A long-term focus that is able to equip patients with the skills and knowledge to be able to cope with life after stroke is essential. Implicit to this focus is an emphasis on the social context of nursing practice in settings other than the clinical rehabilitation environment.

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